2014

# Post-school adult life for young people with Down syndrome

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## Recommended Citation

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# USE OF THESIS

# Post-school adult life for young people with Down syndrome

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This thesis is presented for the award of Doctor of Philosophy

# Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

i. incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;

ii. contain any material previously published or written by another person except where due reference is made in the text of this thesis; or

iii. contain any defamatory material.

This thesis contains published work and work prepared for publication, some of which has been co-authored. The bibliographical details of the work are presented for each paper. The work involved in designing the studies described in this thesis was performed primarily by Kitty-Rose Foley (the candidate).

The thesis outline and experimental design was planned and developed by the candidate, in consultation with Dr Sonya Girdler and Dr Helen Leonard (the candidate's supervisors).

The candidate was responsible for data collection, data management and data analysis. Research assistance provided assistance in data management. The candidate drafted the original thesis with Dr Sonya Girdler and Dr Helen Leonard providing feedback on drafts until the examinable version was finalised.

Candidate signature:

Primary supervisor signature:

# Acknowledgements

First and foremost I would like to acknowledge and warmly thank the support and assistance of my supervisors, Dr Sonya Girdler and Dr Helen Leonard. Sonya, I would like to thank for her forever positive outlook, her belief in my potential as a student and as an Occupational Therapist and for infecting me with her passion to make a difference for people with disabilities. I would like to acknowledge Helen's inspirational devotion to her work and her obvious desire to improve the lives of people with intellectual disabilities. Also, Mrs Jenny Bourke, Mr Peter Jacoby and Ms Ami Bebbington who all provided valuable contributions to this thesis and assisted me to weave my way through the world of statistics.

Thank you to my mentor, Professor Andrew Whitehouse, for his pearls of wisdom and for providing perspective. I feel blessed to have had the opportunity to be a part of the Telethon Institute for Child Health Research, a place with a magical atmosphere of hope and potential.

I am very grateful to the families and the young adults with Down syndrome who took part in this research. The commitment of these families to participate in this research is inspiration in itself and a testament to their desires of improving outcomes for people with disabilities. Thank you to the support and input from the Down syndrome Association of Western Australia, the Department of Education, Disability Services Commission, Edge Employment, Edith Cowan University and the members of the Down syndrome parent group.

I would like to acknowledge and gratefully thank my family, my brothers, my sister and my parents. Your consistent support and encouragement could not be masked by your cheeky ways. My closest friends who got me through the more challenging

parts of this journey, thank you for keeping laughter in my life – I love you all. A very special thank you to my biggest brother Ben, for showing us all how life is supposed to be lived, you are always in my heart.

*“To be truly radical is to make hope possible, rather than despair convincing”*

*- Raymond Williams (1921-1985)*

# Abstract

Down syndrome is a chromosomal birth disorder affecting one in 650 to 1000 live births in Western Australia. The life expectancy for people with Down syndrome has increased dramatically over the past two generations leading to these young people having changing needs in terms of social, economic and personal life. Encompassed within this, is the successful transition from school to post-school, a time of upheaval, stress and important decisions for young people with intellectual disabilities. The International classification of functioning, disability and health (ICF) is a world renowned framework which provides a scientific basis and standardised language for describing and classifying health domains, health-related states and health outcome measurement. To examine the complex and fluid concept of transition from school to post-school for young people with Down syndrome this thesis employed the ICF as a guiding framework.

The purpose of Study one was to describe the relevant literature on this transition for young people with an intellectual disability and identify gaps within the current knowledge base.  The review found that the current body of literature on transition rarely considered those with moderate and severe disability and a whole of person approach was needed in future research.

Study two examined the meaning of wellbeing from the perspective of children and young people with disabilities via focus groups. Six themes of the meaning of wellbeing emerged from the data describing, ‘having things to do’ (participation), ‘the importance of good friends’ (relationships), ‘home is where the heart is’ (family factors), ‘nothing seems to stick in my brain’ (anxiety relating to performance at school), ‘you need some way to cool down’ (coping strategies/resilience) and ‘feeling good about yourself’ (personal growth and development).  The usefulness of the ICF in framing and guiding research in disability was strongly evident. Study two provided evidence from the perspective of young people with disabilities of the

importance of participation. This study informed the subsequent studies in this thesis which focused on the transition from school to post-school for young adults with Down syndrome.

The Down syndrome ‘Needs Opinions Wishes’ database is a population-based database of families of young people living in Western Australia with Down syndrome. Data were collected from families at three time points in 2004, 2009 and 2011 via questionnaires as paper copies, over the internet or via phone interviews. Part one addressed factors related to the young person themselves including medical impairments, behaviour, participation in school or post-school occupations, social relationships, accommodation and functioning in activities of daily living. Part two provided information about family functioning and communication, quality of life, agreement between parents and presence of formal and informal supports.

Study three used the data from the 2009 wave of data collection to investigate the relationship between functioning in activities of daily living (ADL) and post-school day occupations of young adults with Down syndrome. In the 2009 wave of questionnaires data regarding post-school day occupations were collected for the first time, and therefore employed for this study. This study was most strongly aligned with the ‘activities’ component of the ICF. Young adults who were reported as functioning better within self-care, community and communication skills were more likely to be participating in open employment or training than those in sheltered employment or day recreation programs.

Study four explored the relationship between family quality of life, day occupations and activities of daily living of the young person with Down syndrome based on the 2009 data. It revealed that families of young people who were participating in sheltered employment tended to report poorer family quality of life than those participating in open employment after adjusting for personal characteristics, behaviour and family income. Inclusion of family supports reduced the strength of this relationship.

Study five explored any relationship between post-school day occupations and changes in a young person’s behaviour via a longitudinal analysis of data from 2004, 2009 and 2011. Behaviour generally improved through adolescence and into early adulthood for young adults with Down syndrome. It was also evident that the behaviour of those participating in open employment for two consecutive years improved compared to those engaged in other day occupations. This study highlighted the potential important influence that environment can have on young person’s behaviour change but also the need for further research on the direction of this relationship.

Finally, Study six, described the social participation of young adults with Down syndrome and examined its relationship with the physical and social environment using data from 2011. Study three, four and five were aligned with different components of the ICF and examined their relationship with the component of participation. This study was again aligned with the participation component of the ICF yet examined different domains to those previously investigated. This study was also strongly aligned with the environment component of the ICF. It revealed that young adults participation in social roles was more influenced by the physical than the social environment, however both associations were weak. The most commonly reported barriers to participation were attitudes of strangers, support from friends, availability of jobs and public transport. The most commonly cited facilitators to a young person’s participation were family and close friends, young person’s current workplace (if they were employed), and attitudes of superiors and colleagues of the young person.

Overall this thesis provides information on the interactions between the different components of the ICF for young people with Down syndrome who are transitioning from school to post-school. Domains of participation have been explored in detail revealing the important influence of environmental factors on social participation. Participation in different post-school day occupations was associated with changes in behaviour and linked with family quality of life. These findings add substantial knowledge to this field of research and have the potential to guide policy development and future intervention studies.

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**Foley, K.-R**., Dyke, P., Girdler, S., Bourke, J., & Leonard, H. (2012). Young adults with intellectual disability transitioning from school to post-school: a literature review framed within the ICF. *Disability and Rehabilitation*, 1-18.

### Chapter 3

**Foley, K.-R**., Blackmore, A. M., Girdler, S., O'Donnell, M., Glauert, R., Llewellyn, G., et al. (2012). To feel belonged: the voices of children and youth with disabilities on the meaning of wellbeing. *Child Indicators Research, 5, 375-391*.

### Chapter 4

**Foley, K.-R**., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., et al. (2013). Functioning and post-school transition outcomes for young people with Down syndrome. *Child: Care, Health & Development*, *39, 6, 789-800.*

### Chapter 5

**Foley, K-R.,** Girdler, S., Downs, J., Jacoby, P., Bourke, J., Lennox, N., Llewellyn, G., Parmenter, T., & Leonard, H. (2014). Family quality of life is associated with the day occupations of young people with Down syndrome. *Social Psychiatry and Psychiatric Epidemiology.*

### Chapter 6

**Foley, K-R.,** Jacoby, P., Einfeld, S., Girdler, S., Bourke, J., Riches, V., & Leonard, H. (In press). Day occupation is associated with psychopathology for adolescents and young adults with Down syndrome. *BMC Psychiatry.*

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# Additional Scientific Publications

**Foley, K.-R**., Downs, J., Bebbington, A., Jacoby, P., Girdler, S., Kaufman, W., et al. (2011). Changes in gross motor abilities of girls and women with Rett syndrome over a 3- to 4- year period. Journal of *Child Neurology, 1-9.*

Scott, M., **Foley, K.-R.,** Bourke, J., Leonard, H., & Girdler, S. (2013). "I have a good life": the meaning of wellbeing from the perspective of young adults with Down syndrome. *Disability and Rehabilitation*.

**Foley, K.-R.,** Bourke, J., Einfeld, S. L., Tonge, B. J., Jacoby, P., & Leonard, H. (Under review). Depressive symptoms and social relating behaviours persist into adulthood for people with Down syndrome. *Medicine.*

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# Additional Publications

**Foley, K-R**. (August 2013) Title: “Transition” Published in *Voice: Employment and community participation* Down syndrome Australia.

# Conference Presentations

**Foley, K-R.,** Jacoby, P., Girdler, S., Bourke, J., Pikora, T., & Leonard, H. Depression symptoms are sustained into adulthood for young adults with Down syndrome. *International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Asia-Pacific 3rd Regional Conference*, Japan, Tokyo, 2013 (Oral presentation)

**Foley, K-R.,** Jacoby, P., Girdler, S., Bourke, J., & Leonard, H. Impact of health and function on post-school day occupations for young people with Down syndrome. *Australian Association of Developmental Disability Medicine Conference (ADDM)*, Sydney, 2012 (Oral presentation)

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**Foley, K-R.,** Jacoby, P., Girdler, S., Bourke, J., & Leonard, H. Functioning of young adults with Down syndrome transitioning into post-school day occupations. *International Association for the Scientific Study of Intellectual Disabilities (IASSID) World Congress*, Halifax, Scotland, Nova Scotia, 2012 (Oral presentation)

**Foley, K-R.,** Jacoby, P., Girdler, S., Bourke, J., & Leonard, H. Family quality of life of young adults with Down syndrome transitioning from school to post-school. *International Association for the Scientific Study of Intellectual Disabilities (IASSID) World Congress*, Halifax, Scotland, Nova Scotia, 2012 (Oral presentation)

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*Annual Conference for the Australasian Society for Intellectual Disability*, Wellington, New Zealand, 2012 (Poster presentation)

**Foley, K-R**., Jacoby, P., Girdler, S., Bourke, J., & Leonard, H. Young adults with Down syndrome and transition from high-school. *Occupational Therapy Australia 24th National Conference and Exhibition*, Gold Coast Convention and Exhibition Centre, 2011 (Oral presentation)

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# Chapter 1: Introduction

## 1.1 Background

Down syndrome occurs in 1 in every 650 to 1000 live births and is the most common genetic cause of intellectual disability (Bittles, Bower, Hussain, & Glasson, 2006; Bower, Leonard, & Petterson, 2000; Frid, Drott, Lundell, Rasmussen, & Anneren, 1999; Leonard, Bower, Petterson, & Leonard, 1999). Life expectancy for individuals with this chromosomal disorder has increased from approximately twelve years to sixty years in the past two generations, resulting in the need for a re-appraisal of whether the medical and social needs of people with this disorder are currently being met (Bittles et al., 2006; Msall et al., 1994; Roizen & Patterson, 2003; Rusmussen, Wong, Correa, Gambrell, & Friedman, 2006). One such area for appraisal is the transition experience from school to post-school. Post-school transition has been defined as the "life changes, adjustments, and cumulative experiences that occur in the lives of young adults as they move from school environments to more independent living and work environments" (Wehman, 1996, p. 4). For the purpose of this thesis, transition was defined as such and referred to by the terms 'transition' and 'post-school transition' interchangeably. Post-school transition is a gradual process of assuming new and different adult social roles and is considered a challenging period of family adjustment for which there is often little preparation (Clegg, Sheard, Cahill, & Osbeck, 2001; Spring, Rosen, & Matheson, 2002; Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006b). Research has shown that adult services appear to be disjointed and unprepared for young adults with developmental disabilities who rightfully expect to participate in society as full citizens (Binks, Barden, Burke, & Young, 2007).

Transition to adulthood for school leavers has been described as a time of upheaval, stress and important decisions and is a period marked by uncertainties and challenges (Caton & Kagan, 2006; Kim & Turnball, 2004). For parents of young adults with disabilities it has been paralleled with the moment of diagnosis, described by parents as the 'second shock' (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). The role of families in supporting, forward planning and being proactive in the transition process has been highlighted as paramount to achieving successful transition outcomes for their son/daughter (Heslop & Abbott, 2007; Kim & Turnball, 2004). Research has reported many negative impacts on the family as a result of this stressful transition time (Blacher, 2001; Heller & Factor, 1993; May, 2001; Nuehring & Sitlington, 2003). Positive influences have also been reported with families in Western Australia reporting personal growth and enhanced personal resources in relation to stressful events and chronic demands encountered during this transition period (Rapanaro, Bartu, & Lee, 2008). There is a paucity of literature which has examined the association between transition outcomes and individual and society factors.

Children and young people with Down syndrome experience a range of comorbidities and high variability in functioning in all areas of development (Roizen & Patterson, 2003). Common comorbidities include cardiac, gastro-intestinal, thyroid, respiratory and musculoskeletal conditions (Thomas et al., 2010). Many children and young people with Down syndrome also experience hearing loss. A Norwegian study reported 26% of their sample had mild hearing impairments, 6% moderate and 2% severe (Prasher, Chung, & Haque, 1998). An Australian population-based study reported 59% of their sample had an ear or hearing issue, however, this included 'Glue ear' a common ailment in normative populations (Thomas et al., 2010). Vision impairments were also commonly reported specifically short and long-sightedness, strabismus and astigmatism. Vision and hearing impairments have the potential to influence participation along with other impairments of body functions and structures.

The level of participation in social, work, leisure and community activities among young adults in Australia with Down syndrome is relatively unknown. In Taiwan a recent study of patterns of participation of 997 adolescents with Down syndrome revealed little diversity and intensity of participation (Wuang & Chwen-Yng, 2012). These authors found that the young people with better motor and cognitive functions participated more and reported greater enjoyment in both formal and informal activities (Wuang & Chwen-Yng, 2012). A study of school age children with Down syndrome in Australia reported that all children predominantly participated in solitary and sedentary activities and that those with better functional abilities were more likely to report to have more friends (Oates, Bebbington, Bourke, Girdler, & Leonard, 2009). Relationship between higher IQ and success in participating in different activities has been reported by other researchers (Carr, 2003; Dulaney & Tomporowski, 2000; Wuang & Su, 2011). Also in Australia, Tuckerman and colleagues (2012) explored employment trends for people with disabilities since 1986. They found there was large differences by type of disability and that the number of those with intellectual disability participating in open employment has not increased with the numbers of those with other disabilities (Tuckerman, Cain, Long, & Klarkowski, 2012). Further research is needed to better understand participation for young people with Down syndrome across many areas of life including leisure, work and community activities.

### 1.1.1 Australian Policy

In Australia in the 1970s and early 1980s Parmenter reported that Australia was being influenced by a number of social, philosophical and political forces including the increasing influence of the normalization principle for people with intellectual disabilities (Parmenter, 1999). In 1983 the Federal Government sponsored three major initiatives to change disability services in Australia. One of which was setting up the Handicap Programs Review. As a result of this review, which included consultation with people with disabilities, their families and services providers, the New Directions Report of the Handicapped Programs Review was published and the Disability Services Act enacted (Disability Services Act, 1986; Grimes, 1985).

The Disability Services Act (DSA) aimed to promote more positive outcomes through integrated services that were flexible and responsive to the needs of people with disabilities. The DSA enabled the creation of a range of disability services including two new types of employment services; open employment services and supported employment services. However, nine years after the DSA was introduced, a review found that the need for services far exceeded the provision and that there were no data about levels of demand, unmet need or characteristics of potential target groups (Baume & Kay, 1995). A recent exploration of employment trends in Australia revealed a concerning picture for people with intellectual disabilities and rates of employment in open environments in comparison to people with other disabilities. The number of people with intellectual disability participating in open employment has remained relatively stagnant from 1999 to 2010 compared to a 186% increase for people with other disabilities (Tuckerman et al., 2012).

Disability services in Australia are now facing a potential revolution of how supports and services are accessed and funded with the introduction of the National Disability Insurance Scheme (NDIS). The NDIS will be implemented by DisabilityCare Australia, an independent statutory agency (Productivity Commission, 2011). The scheme consists of three tiers; Tier 1 will be concerned with promotional activities and activities which aim to maximize social participation and research and data gathering capabilities. Tier 2 will be about information sharing, referral and web-services and Tier 3 is aimed at those with a significant need for disability support and early intervention (Productivity Commission., 2011). The first stage of the Scheme has been rolled out in 2013, highlighting this as an exciting time as services are being re-shaped to better meet the needs of people with disabilities and their families. In view of these service provision changes, this thesis provides important information to facilitate and help guide the re-shaping of services for people with intellectual disability who are transitioning from school to post-school.

### 1.1.2 International policy

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was held in 2006 with the purpose to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (United Nations, 2006, Article 1 - Purpose). The convention covers many areas of life including; the rights of women with disabilities, rights of accessibility, access to justice and security, freedom from abuse, integrity, living independently, privacy, home and family, education, health, rehabilitation, work and employment, participation in political and public life, participation in cultural life, recreation, leisure and sport and data collection. The period of transition from school to adulthood is a time when many young people with intellectual disability begin to face the challenges related to the Rights stated in the convention.

To support the implementation of the UNCRPD, the World Health Organization called for a World Report on Disability. This report was published in 2011 and pinpointed disabling factors in the environment and how these affected the lives of people with disability (World Health Organization, 2011). Some of the disabling barriers to participation for people with disabilities included; inadequate policies and standards, negative attitudes, problems with service delivery, lack of accessibility, lack of consultation and involvement and lack of rigorous data and evidence. The disadvantages that people with disability experience as a result of these factors were poorer health outcomes, lower education attainment, higher rates of poverty and not being able to live independently or participate fully in community activities. Lack of participation was attributed to reliance on institutional solutions, inaccessible transport and other public facilities, negative attitudes of the general population meaning that people with disabilities were dependent on others and isolated from mainstream social, cultural, and political opportunities (World Health Organization, 2011). Specifically, the world report highlights how people with intellectual disabilities are particularly excluded in areas such as employment and face negative treatment and abuse (Officer & Shakespeare, 2013; World Health Organization, 2011).

Another plan which resulted from the UNCRPD was the "Incheon Strategy to Make the Right Deal for Persons with Disabilities in Asia and the Pacific" (United Nations, 2012). The Incheon Strategy was based on UNCRPD principles to accelerate disability-inclusive development and UNCRPD ratification and implementation. Ten goals of the Incheon Strategy were outlined and of main interest for this thesis is Goal 1 and Goal 3. Goal 1 aims to reduce poverty and enhance work and employment prospect, and Goal 3 aims to enhance access to physical environments, public transports, knowledge, information and communication. Goal 5 addresses expanding early intervention and education of children with disabilities and specifically mentions children with intellectual disability in the core indicators. The indicator is to increase the proportion of children with intellectual disabilities enrolled in primary and secondary school in order to track progress. People with intellectual disability are specifically mentioned in the policy direction as a group that needs to be empowered (United Nations, 2012).

It is well recognized through the world report, the Incheon Strategy and others, that the experience of disability is an outcome of the interaction between the person with a health condition and environmental factors. Research describes people with disabilities as being further disabled by environmental factors rather than the disability being a feature of the individual (Schneidert, Hurst, Miller, & Ustan, 2003).

Therefore to improve outcomes for people who are disabled, it is of upmost importance to first identify what those disabling factors are (Schneidert et al., 2003). For young people with Down syndrome transitioning from school to adulthood there is a multitude of complex interactions between environment and individual characteristics which have the potential to influence execution of tasks and participation in both community and societies. The International, Classification of Functioning, Disability and Health provided a guiding framework to examine these associations within a structured and understandable approach.

### 1.1.3 International classification of functioning, disability and health

The International classification of functioning, disability and health (ICF) presents a framework which provides a scientific basis and standardised language for describing and classifying health domains, health-related states and health outcome measurement (World Health Organization, 2001). The ICF framework encompasses three components. Body functions and structures, describes the anatomical parts and physiological functioning of a person. Loss of physiological functioning or damaged body structures are referred to as 'impairments.' The second component of the ICF, activity, refers to the execution of a task and the ease with which this is done. Issues with completing a task or activity are described as 'activity limitations.' The third component describes involvement in a life situation, or participation with difficulties described as 'participation restrictions' (Stucki, 2005; World Health Organization, 2001). These three components are classed within the umbrella terms of functioning and disability. The impact of contextual factors, both environmental and personal factors, are also considered within the framework (refer to Appendix A).

A second version of the ICF was released in 2007, the International classification of functioning, disability and health for children and youth (ICF-CY) (World Health Organization, 2007). The ICF-CY expanded on the content of the components of the ICF by including documentation of child characteristics from infancy through to adolescence (Simeonsson, 2009). It has the same hierarchical structure as the ICF but is considered more applicable for those from birth to 17 years of age. Through extensive field trials a number of codes were added to the ICF-CY and some removed. An example of codes which were deemed not applicable for children and youth were codes relating to menopause. Some examples of communication codes which were added to the ICF-CY include; solitary, parallel, and cooperative play, acquiring single words of syllables, acquiring correct syntax, orientation to objects and acquiring skills to recognise symbols, characters and alphabet (World Health Organization, 2007). For the purpose of this thesis, the ICF, rather than the ICF-CY was chosen as the guiding framework, due to the ages of the majority of participants being older than 18 years and the codes within the ICF being more applicable to the young adult cohort (e.g. employment codes). The use of the ICF provided a relevant framework which enabled an understanding of the experience of transition from school to post-school for young people with Down syndrome.

## 1.2 Down syndrome 'Needs Opinions Wishes' study

The Intellectual Disability Exploring Answers (IDEA) database was formed in 2003 and was established to provide an infrastructure for research and to facilitate the planning of service provision for people with intellectual disabilities (Petterson et al., 2005). The database contains information about people with an intellectual disability in Western Australia. Ongoing case ascertainment occurs through Disability Services Commission and the Department of Education (Petterson et al., 2005).

Participants in the Down Syndrome Needs Opinions Wishes (NOW) study were recruited from the IDEA database and contact was made through the Disability Services Commission. Families of children with Down syndrome aged between 0 and 25 years, identified from these various sources, were invited to participate in the Down syndrome NOW study in 2004 (n=500). There were three waves of data collection in the Down syndrome NOW study in 2004, 2009 and 2011 (refer to Appendix B, C and D for 2004, 2009 and 2011 Down syndrome NOW questionnaires, respectively). At each wave families were mailed questionnaires, and if they were returned, consent was inferred. Follow-up phone calls were undertaken to explain the study and check whether families had received the questionnaires. A number of phone interviews also took place where the families preferred this method of questionnaire administration. At all three time points the questionnaires were available via the internet, allowing participants to complete online.

The questionnaires differed slightly from 2004, 2009 and 2011 however the information collected was broadly aligned. The questionnaires contained two parts; part one, addressed information on health, functioning and service needs, while part two examined the health and wellbeing of the family. In 2009 an additional section was added, specifically addressing transition issues. In 2011, additional sections were added and addressed nutrition, social participation and the influence of the environment. The specific outcome measures included within each questionnaire are shown in Table 1. Of specific relevance to this thesis, were the data collected on participation in post-school day occupations. These data were collected in the 2009 and 2011 waves of questionnaires. Young people with Down syndrome were reported to participate in open employment, training, sheltered employment and/or day recreation programs. Open employment described those who were working in a mainstream setting often with support; training described further education such Technical and Further Education (TAFE); sheltered employment, work in a segregated setting for people with disabilities currently referred to as ‘Australian Disability Enterprises’ in Australia; and day recreation programs or ‘Alternative to Employment’ programs for people with disabilities who were unable to participate in employment or further training (Disability Services Commission, 2009). There were also a number of young people who were reported as remaining at home with family or peers. These classifications of day occupations are referred to throughout this thesis and are interchangeably described in the singular and plural (occupation/occupations) as young people may have been participating in one or more occupations at one time.

In 2004 73% of questionnaires were returned (n=362/500) providing a wealth of population-based data of child/young adult and family factors. The denominators for the response fractions were the number of families who confirmed they had received the questionnaires. In 2009, 88.6% (n=203/229) and in 2011, 88.8% were returned (n=198/223).

Throughout the development of the Down syndrome 'Needs Opinions Wishes' study a consumer reference group was formed and industry partners consulted. The consumer reference group was made up of mothers of young adults with intellectual disabilities and met bi-annually. This group provided valued input and facilitated the enhancement of the research processes, outputs and outcomes. Additionally, industry partners, who included representatives from Disability Services Commission, Department of Education, employment support services and non-government agencies working with young people with intellectual disability also were involved and regularly consulted. It is now expected by the National Health and Medical Research Council in Australia that researchers work in partnership and involve consumer and community representatives in health and medical research (National Health and Medical Research Council, 2002; McKenzie & Hanley, 2007; Payne, D'Antoine, France, McKenzie, Henley et al., 2011).

## 1.3 Significance of the study

The right to participate in cultural, recreational and leisure activities, to participate in public life, the right to work and employment, to health and education, the right to access information and to live independently and the right to physical accessibility for people with intellectual disabilities are now human rights (United Nations, 2006). This thesis explores the realities of these areas of life for young people with Down syndrome transitioning from school to adulthood in Western Australia. The World

Health Organization recommends the universal use of the ICF in disability research, therefore this study is framed within this internationally recognized framework.

Employing both qualitative and quantitative methodologies informs an approach allowing for triangulation of methodologies, which in turn, leads to an enriched response to the research problem (Jick, 1979). Very little research has actively sought the experiences and perceptions of children and young people with disabilities and their families. This is vital when exploring inherently individual and multi-faceted concepts such as wellbeing and participation. This thesis employed qualitative methods to ascertain the perspective of children and young people with disabilities on the meaning of their wellbeing, providing invaluable insights into their experiences.

This thesis adds new knowledge as it is the first longitudinal examination of the transition experience for young adults with Down syndrome in Australia. Longitudinal data enabled examination of those factors which were associated with transition outcomes among young adults with Down syndrome. There are considerable gaps in research related to transition from school to post-school for young adults with Down syndrome, with most research focused on singular outcomes and only including those with mild intellectual disability. The population-based sample ensured inclusion of young adults of varied ability avoiding selection bias, and increased the ability to generalise the study findings. The large number of participants in the Down syndrome NOW study increased power allowing for statistical analyses of the data with minimal error and the provision of tighter confidence limits (Portney & Watkins, 2000). This study provides important insights into the complexity of the transition experience for young adults with Down syndrome and provides evidence to guide service delivery, influence policy changes and address issues relates to the UNCRPD.

## 1.4 Purpose of the study

Given the significance stated in the previous section, the literature reviewed and the need for research in this area, the purpose of this thesis was to examine the experience of transition from school to post-school for young adults with Down syndrome and investigate factors which are positively and adversely associated with different outcomes in adulthood. The ICF was used as a guiding framework to investigate how factors including functioning in activities of daily living, psychopathology, participation in occupation and leisure activities, family quality of life and environmental factors were associated during the transition from school to adulthood for young adults with Down syndrome.

## 1.5 Research questions and hypothesis

The overall aim of the proposed research was to examine the experience of transition from school to post-school for young adults with Down syndrome and investigate factors which were positively and adversely associated with different outcomes in adulthood. Specifically, the proposed research involved six studies, four of which were each aligned predominantly with one domain of the ICF (See Figure 1). The six studies are summarised in Table 2. The aims of the six studies in this thesis were:

Study One: Literature review framed within the ICF

- Describe literature relating to transition for young people with an intellectual disability and identify gaps within the current knowledge base.

Study Two: Perceptions of children and youth with disabilities

- Describe the meaning of wellbeing for children and youth with disabilities from their perspective.

Study Three: Young person functioning and day occupation

- Investigate the relationship between functioning in activities of daily living (ADL) and post-school day occupations for young adults with Down syndrome.

Table 1: Measures by ICF domain and wave of questionnaire

| ICF Domain | Measure | Q2004 | Q2009 | Q2011 | Subject of measure Parent/ Family | Subject of measure Young adult |
|---|---|---|---|---|---|---|
| Body structures and function | Developmental Behaviour Checklist (DBC) (Einfeld & Tonge, 1995) | | | | | X |
| Activity | Index of Social Competence (McConkey & Walsh, 1982) | | | | | X |
| | WeeFIM (Msall et al., 1994) | X | X | X | | X |
| Participation | Assessment of Life Habits (LIFE-H) (Noreau, Fougeyrollas & Vincent, 2002) | | | X | | X |
| Environmental Factors | McMasters Family Assessment Device (Epstein, Baldwin & Bishop, 1983) | X | X | X | X | |
| | SF-12 (Ware, Kosinski & Keller, 1996) | X | X | X | X | |
| | The Depression, Anxiety, Stress Scales (DASS) (Lovibond & Lovibond, 1993) | X | X | X | X | |
| | Measure of the Quality of the Environment (MQE)(Fougeyrollas, Noreau, St-Michael & Boschen, 2008) | | | X | | X |
| Personal Factors | Socio-demographic information, age race, gender, social background and past experiences. | X | X | X | X | X |
| | Quality of Life Measures | | | | | |
| QOL Measure | | Q2004 | Q2009 | Q2011 | Subject of measure Parent/ Family | Subject of measure Young adult |
| | Personal Well-being Index (Cummins et al., 2005) | | X | X | | X |
| | Beach Centre Family QOL Scale (Hoffman et al., 2006) | | X | X | X | |

*Note.* ICF, International classification of functioning, disability and health, QOL, Quality of Life

*Note.* All measures were parent report

- Identify factors which influence the relationship between functioning and day occupation including the individual's physical and mental health, the type of school attended, the mother's emotional state and the level of involvement of both the young person and their parents in transition planning.

Study Four: Family quality of life and young person post-school day occupations

- Describe the quality of life of families with a young adult with Down syndrome who had recently transitioned from school to post-school.
- Investigate the influences of the young person's post-school day occupations and personal and environmental factors on family quality of life.

Study Five: Young persons changes in behaviour and post-school day occupations

- Describe behaviour changes overtime for young people with Down syndrome.
- Explore the relationship between post-school day occupations and young persons change in behaviour.

Study Six: The influence of environmental factors on young people's social participation

- Describe the social participation of young adults with Down syndrome and examine its relationship with the physical and social environment.

## 1.6 Candidate's role

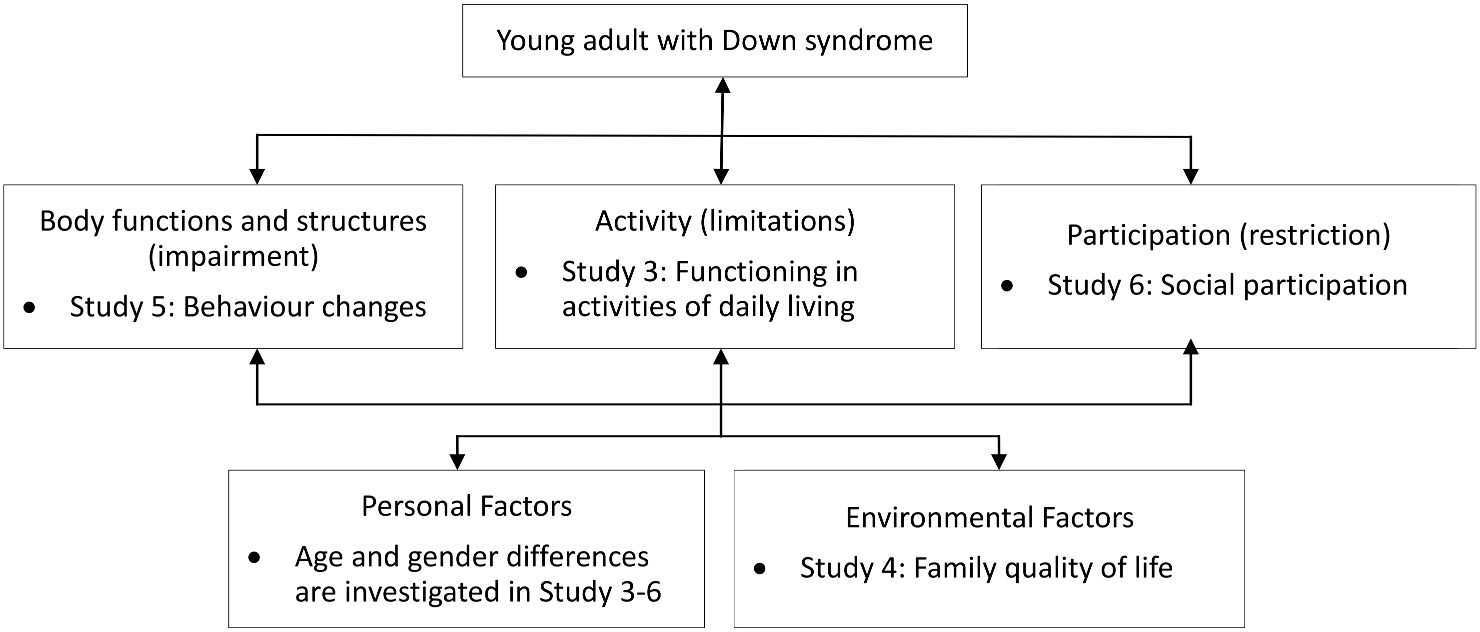
This study spans research collected over a seven-year period. The first wave of questionnaires were collected in 2004, prior to the candidates project. The second wave of questionnaires were collected during 2009 and early 2010. The candidate assisted in collecting the 2009 questionnaires through phone calls to families and follow up letters and emails. This was conducted in collaboration with a research assistant. The candidate was responsible for data entry and data cleaning of both 2004 and 2009 questionnaires. The research assistant contributed to data entry.

The 2011 questionnaire was primarily designed and assembled by the candidate. The candidate and a research assistance distributed questionnaires via the mail. An external source was used to develop the online version of the questionnaire. The research assistant conducted the phone interviews with those families who preferred not to complete the questionnaire online or via a paper copy. The candidate and the research assistant collected questionnaires and followed up families who had not responded. All data cleaning, coding and analysis were carried out by the candidate with consultation from a statistician. Prior to distribution of the 2011 questionnaires families were mailed a booklet which contained lay summaries of descriptive results from the 2004 and 2009 questionnaires. The candidate played a central role in developing this resource.

The candidates' roles in the qualitative study described in chapter three were to analyse transcripts and scribes notes from the focus groups. The candidate was not involved in data collection for the qualitative study. The candidate coded and analysed all data and wrote the publication. The candidate's supervisor and other contributing authors reviewed drafts and provided feedback for consideration by the candidate.

The candidate independently designed the overall concept and wrote all sections of this thesis. Drafts of each section were reviewed by the candidates' supervisors and other contributing authors and adjusted accordingly.

Figure 1: Study 3 to 6 classified within the ICF domains



*Note.* This figure has been reproduced with permission from the World Health Organization

Table 2: A summary of the methods used in each of the studies in this thesis

| Study | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| Approach | Literature review | Qualitative focus groups with children and young people with disabilities | Cross-sectional, questionnaire based study | Cross-sectional and qualitative, questionnaire based study | Longitudinal, questionnaire based study | Cross-sectional, questionnaire based study |
| Analyses design | Systematic review of studies relating to intellectual disability and transition from school framed within the ICF | Six focus groups with the primary aim of defining the meaning of wellbeing from the perspective of children and young people with disabilities | Compared functioning in ADL of young people with Down syndrome attending different day occupations | Compared family QOL of young people with Down syndrome attending different day occupations | Compared change in behaviour overtime of young people with Down syndrome attending different day occupations | Explore the relationship between social participation and environmental factors |
| Year of Down syndrome 'NOW" questionnaire data | NA | NA | 2009 | 2009 | 2004, 2009 and 2011 | 2011 |
| Type of data | Text | Focus groups | Categorical, ordinal | Categorical, ordinal and open ended answers to questions | Interval, categorical and ordinal | Categorical, ordinal |
| Statistical methods | NA | Open coding and constant comparison methods | Chi-square, analysis of variance, logistic regressions | Chi-square, analysis of variance, linear regressions | Chi-square, analysis of variance, linear regression with change score | Chi-square, analysis of variance, linear regressions |

*Note.* NOW, Needs, Opinions, Wishes Study, ICF, International classification of functioning, disability and health, ADL, Activities of daily living, QOL, Quality of life

## Preface to chapter two

Chapter two of this thesis presents a literature review of research with people with intellectual disability and the transition from school to post-school. The review is framed within the ICF. This review was published in *Disability and Rehabilitation* in 2012. The full, published manuscript is provided as Appendix F.

The PhD Candidate, Kitty-Rose Foley accounted for 85% of the intellectual property associated with the final manuscript. Collectively, the remaining authors contributed 15 per cent.

# Chapter 2: Literature review framed within the ICF

## YOUNG ADULTS WITH INTELLECTUAL DISABILITY TRANSITIONING FROM SCHOOL TO POST-SCHOOL: A LITERATURE REVIEW FRAMED WITH THE ICF

### 2.1 Abstract

Purpose: The purpose of this review was to describe literature relating to transition for young people with an intellectual disability and identify gaps within the current knowledge base.

Method: A narrative literature review was undertaken. Searches of databases Medline, CINAHL, PsycINFO, ERIC, ISI Web of Science and ProQuest 500 International provided relevant research articles. The search terms used were intellectual disability, transition, employment and ICF as well as other terms derived from the ICF. Manual searches of reference lists identified additional studies. Furthermore, government websites were searched for relevant reports and policies.

Results: Transition literature was explored by ICF domains; body functions and structures, activity and participation and contextual factors. Studies were identified in some but not all areas and included literature describing self-determination and participation in leisure activities for those with mild intellectual disability. However, significant gaps were found particularly for those with severe intellectual disability.

Conclusions: The ICF is a useful tool in framing a review of transition literature for young people with intellectual disability due to the complexity and multi-faceted nature of transition. The important influence of environmental factors including family systems, post-school services and access to transport were highlighted as having considerable impacts on transition outcomes.

## 2.2 Introduction

The term post-school transition has been commonly used to describe the crucial task of moving from the protected life of a child to the autonomous and independent life of an adult. Individuals vary substantially in their experiences and the rate at which they transition. The transition of adolescents with an intellectual disability to adult life is characterised by wider scope, longer duration and attenuated experiences than for those without an intellectual disability (Hudson, 2003; May, 2000; Michaels & Lopez, 2005). Transition has been reported by families and caregivers as a time of upheaval, stress and important decisions, and there is much confusion about services available (Caton & Kagan, 2006). Challenges which research into post-school transition is yet to overcome include the bias towards people with mild intellectual disability, accurately describing the psychological experience of transition, and the strong focus on employment and autonomy alone (Clegg et al., 2001). Exploring and facilitating the complex and multi-faceted transition process for young people with intellectual disabilities has now become an important concern internationally for service providers and researchers working within this area.

The International classification of functioning, disability and health (ICF) presents a framework which provides a scientific basis and standardised language for describing and classifying health domains, health-related states and health outcome measurement (World Health Organization, 2001). More recently, the Children and Youth Version (ICF-CY) was developed, extending this framework for younger age ranges (World Health Organization, 2007). The ICF framework encompasses three components. Body functions and structures, describes the anatomical parts and physiological functioning of a person. Loss of physiological functioning or damaged body structures are referred to as ‘impairments.’ The second component of the ICF, activity, refers to the execution of a task and the ease with which this is done. Issues with completing a task or activity are described as ‘activity limitations.’ The third component describes involvement in a life situation, or participation with difficulties described as ‘participation restrictions’ (Stucki, 2005; World Health Organization, 2007). These three components are classed within the umbrella terms of functioning and disability. The impact of contextual factors, both environmental and personal factors, are also considered within the framework. The ICF, rather that the ICF-CY was chosen as the guiding framework for this review as the age ranges of young people with intellectual disability who are transitioning from school to adulthood are better aligned with the ICF (18 years and older). Additionally, in the ICF, there are domains related specifically to employment, which is an important concept when considering the transition from school to post-school (World Health Organization, 2001).

The aim of this review was to describe current literature relating to transition for young people with an intellectual disability and highlight the weaknesses and gaps within the current knowledge base. The specific goals of this review were to; 1) employ the ICF as a framework to describe transition literature, 2) describe transition issues internationally and evaluate the similarities and differences in Australia, 3) describe changes in transition policy and services over time and identify impacts on outcomes, and 4) evaluate and describe the methodological challenges in transition research with young adults with intellectual disability.

## 2.3 Methods

A narrative literature review was undertaken due to the paucity of research in this area. To locate literature relevant to the purpose of this review the databases Medline (1966-2011), CINAHL (1982-2011), PsycINFO (1920-2011), ERIC (1992-2011), ISI Web of Science (1992-2011) and ProQuest 500 International (1938-2011) were searched from their earliest records to most recent. The search terms used were intellectual disability, Down syndrome, adulthood, transition, employment, occupation, school, post-school and ICF. These were truncated, exploded and adjusted to achieve optimal results. Manual searches of reference lists of relevant articles were conducted to identify further studies. Additionally, government websites were searched for relevant reports and policies. Studies were included in the review if they involved participants who had an intellectual disability. Outcomes of interest were those relating to the domains of the ICF, body functions and structures, activity and participation and contextual factors. The primary source of references for this review was research articles. Refer to Table 3 for description of literature by type, country, level of evidence and topic. Level of evidence was categorised according to the guidelines set by the National Health and Medical Research Council for quantitative research and guidelines set by expert qualitative researchers for qualitative research (National Health and Medical Research Council, 2009; Daly, Willis, Small, Green, Welch, Kealy, et al., 2007).

## 2.4 Results

All of the research articles in this review were rated as level four (n=61, 63.5%) or five (n-35, 36.5%) on the level of evidence classifications as guided by the National Health and Medical Research Council and the qualitative criteria (National Health and Medical Research Council, 2009; Daly et al., 2007). None of the literature reached a higher level of evidence. Thirty-five articles were opinion or comment pieces (27.3%), thirty-four were quantitative (26.6%) and thirty-seven were qualitative (28.9%) articles. The majority of literature identified for this review emerged from the United States (US) (42.2%), followed by the United Kingdom (UK) (27.3%) and then Australia (16.4%)(Appendix E).

### 2.4.1 Body functions and structures

The body functions and structures component of the ICF describes impairments of physiological functions as well as psychological functioning. Impairments of mental cognition and functions are termed intellectual disability, and result from a range of underlying pathological processes. In 2007 the term ‘intellectual disability’ was

Table 3: Description of literature by type, country, level of evidence and topic

| Description of Literature | n | % |
|---|---|---|
| Type of Literature | | |
| Book | 17 | 13.3 |
| Government/Agency Report | 11 | 8.6 |
| Articles | | |
| Quantitative | 34 | 26.6 |
| Qualitative | 37 | 28.9 |
| Mixed methods (quantitative and qualitative) | 6 | 4.7 |
| Opinion/comment | 35 | 27.3 |
| Total | 128 | 100 |
| Countries | | |
| UK | 35 | 27.3 |
| AUS | 21 | 16.4 |
| US | 54 | 42.2 |
| Europe | 6 | 4.7 |
| Canada | 7 | 5.5 |
| Other | 5 | 3.9 |
| Total | 128 | 100 |
| Level of Evidence | | |
| Four | 61 | 63.5 |
| Five | 35 | 36.5 |
| Total | 96 | 100 |
| Topics | | |
| Intellectual Disability and Transition | 34 | 26.6 |
| ICF | 14 | 10.9 |
| Intellectual disability only | 52 | 40.6 |
| Transition only | 19 | 14.8 |
| Other | 9 | 7.0 |
| Total | 128 | 100 |

*Note.* UK, United Kingdom, AUS, Australia, US, United States, ICF, International classification of functioning, disability and health.

adopted by the American Association on Intellectual and Developmental Disabilities and is now widely recognised as the most appropriate term and henceforth will be used in this paper (Schalock et al., 2007). In the ICF, intellectual disability is classified as an intellectual function, together with intellectual growth, intellectual retardation and dementia, while theoretically excluding higher level cognitive functions and memory (World Health Organization, 2001)

The statistical definition of intellectual disability employs comparison of an individual's performance to the performance of a standardized normative group as measured by intelligence quotient (IQ) tests. The IQ range of scores for each category are; mild intellectual disability (50-55 to approximately 70), moderate intellectual disability (35-40 to 50-55), severe intellectual disability (20-25 to 35-40) and profound intellectual disability (IQ below 20 or 25).

Defining intellectual disability has been challenging, and further refinement and standardization is required (Wen, 1997). The most recent revision to the definition, by the American Association of Intellectual and Developmental Disabilities (AAIDD), includes measure of IQ and adaptive behaviour, and levels of support needed to function in the community (Schalock et al., 2010). Recent research in the US with intellectually disabled young adults using the ICF framework emphasized the need to examine impairment by type and severity in order to adequately understand some of the complexities and differences in the acquisition of adult social roles among this group (Van Naarden Braun et al., 2006b).

A population-based study in Western Australia indicated the prevalence of intellectual disability was 14.3/1000 livebirths, with 10.6/1000 for children with mild or moderate intellectual disability and 1.4/1000 with a severe level of intellectual disability (Leonard, Petterson, Bower, & Sanders, 2003). Prevalence of intellectual disability was 1.6 times greater in males and 2.3 times greater in children of Aboriginal mothers (Leonard et al., 2003). In a cohort of 9,703 people in Western Australia, 35% had a biomedical cause for their intellectual disability, 5% were diagnosed with autism and for over 50% the cause was unknown (Leonard et al., 2004). Of the 35% with a biomedical diagnosis for their intellectual disability, the most common diagnosis was Down syndrome (15%) followed by genetic abnormalities and birth defects (12%), infections (4%) and other medical, chromosomal or toxic causes (4%) (Leonard et al., 2004). Common health issues in adolescents and young adults with intellectual disability are epilepsy, gastrointestinal problems, thyroid disease, obesity, and musculoskeletal problems related to spasticity and/or hypotonia. The prevalence of vision and hearing problems is also higher than in the general population (Developmental Disability Steering Group, 2005). Additionally, individuals with intellectual disability have been reported to be up to seven times more likely to have a diagnosable psychiatric condition compared to those without an intellectual disability (Emerson, 2003). It has been suggested that youth with intellectual disabilities and co-morbid psychiatric disorders will confront additional barriers and their transition experience will be particularly difficult, specifically in tasks associated with housing, employment and social interactions (Blacher, 2001). These impairments of body functions and structures can have important impacts on a young adult's ability to participate in daily life and transition related activities including attending school or work.

### 2.4.2 Activity and participation

#### 2.4.2.1 Functional skills

Within the activity domain the ICF describes a number of functional skills including self-care, communication and domestic skills. As mentioned the most recent definition of intellectual disability involves consideration of the individual's functional or adaptive skills as well as level of assistance required to complete activities of daily living (Schalock et al., 2010). Research surveying families of young people with Down syndrome in Western Australia (n=363) found that young adults were most independent in their mobility and required the greatest assistance in communication, higher cognitive functions and more complex self care tasks (Dyke, Leonard, Bourke, Bebbington, & Bower, 2007). Over 60% of those aged 18-25 years were able to understand everyday conversations and only about 60% were able to independently express their needs. Just over 40% could independently use the telephone and only 17% were able to use public transport independently.

Isolated impairment does not automatically result in activity limitations or restricted participation, although in severe intellectual disability and/or multiple impairments it does have a large impact across a range of domains (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2009). These limitations then have direct impacts on these young people reaching transition outcomes such as employment. Limitations in activities and instrumental activities of daily living have been shown to be more prevalent in those with intellectual compared to other developmental disabilities (Van Naarden Braun et al., 2009). Evidence from Australia has suggested that the best predictor of future capacity for work among young adults with a disability (40% of whom had an intellectual disability) was the student's ability to manage activities of daily living (Eagar et al., 2006). Behaviour had a weaker association with future capacity for work (Eagar et al., 2006).

#### 2.4.2.2 Interpersonal and social skills

Within the activity and participation domain of the ICF, a range of interpersonal skills and social skills are described including elements of informal social relationships and family relationships. The impact of social skills, independent living skills and leisure activities training included in transition programmes on post-school outcomes has received little attention in the literature. It is known that young adults with intellectual disability commonly find it more difficult than those without an intellectual disability to form friendships, understand and develop sexual relationships, and access and engage meaningfully in their local community (Cory, Dattilo, & Williams, 2006; Devine & Dattilo, 2000; Richard Williams & John Dattilo, 1997). Research from Australia and Israel found that friendships appear to decline for adolescents once they leave the more formal supports of school, and it is primarily through employment and involvement in day activities that new social networks are formed (Duvdevany & Arar, 2004; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Oates et al., 2009). For many the immediate period post transition from school can be a very isolated and lonely time where most social contact is with immediate family or organised by the family (Duvdevany & Arar, 2004). Although transition support models have been developed and strategies suggested as to what is needed to implement these models to assist students with intellectual disability to achieve social, community and civic life outcomes (Hughes, 2001), to date limited research has examined the impact of these on the young adult's wellbeing and participation in adult life.

#### 2.4.2.3 Self-determination

School education and vocational education/higher education or employment are described within the activity and participation domain of the ICF. An emerging concept in transition literature for young people with intellectual disability is the importance of self-determination. Self-determination theory describes an approach to human motivation and involves three essential needs; the need for competence, relatedness and autonomy (Ryan & Deci, 2000; Van Cleve, Cannon, & Cohen, 2006). Exploring the processes and conditions which foster the healthy development and effective functioning of individuals and enabling them to decide what is wanted, rather than have external providers 'plan for' them are key, specifically in vulnerable populations such as people with intellectual disabilities (Laragy, 2004; Ryan & Deci, 2000; Shaddock, Bond, Bowen, & Hales, 2000).

Self-determination has been highlighted as a critical element in optimising outcomes in the process of transition from secondary school to adulthood for youths with intellectual disabilities, particularly in the US (Halloran, 1993; Halpern, 1999; Wehmen, 1993). Self-determination incorporates skills such as goal setting, decision making, problem solving, communication, self-awareness and self-advocacy and has been found to have a significant link with quality of life (Agran, Blanchard, & Wehmeyer, 2000; Lachapelle et al., 2005). Many have assumed that individuals with intellectual disability cannot become self-determined (Wehmeyer & Schwartz, 1998), however this has been disputed by researchers finding that self-determination status is impacted by environmental factors to an equal or greater extent than by personal characteristics (Stancliffe, Abery, Springborg, & Elkin, 2000; Wehmeyer & Garner, 2003; Wehmeyer & Palmer, 2003). People with intellectual disability therefore have the capacity to control their lives in a more meaningful way if supported to do so. Despite this, current research suggests that educators are, on the whole, unfamiliar with the construct of self-determination and how to effectively foster this in youth with intellectual disability (Grigal, Neubert, Moon, & Graham, 2003; Wehmeyer & Garner, 2003). Transition planning and program development provide important opportunities to foster self-determination in students with disabilities (Wehmeyer & Schwartz, 1997). While normalised, community-based environments have been reported to support and enhance self-determination, segregated environments such as congregated living and sheltered employment may limit opportunities for choice and decision-making, diminishing self-determination (Wehmeyer & Bolding, 2001). The value of teaching self-determination skills and behaviour has been described with thought that self-determination training should be a critical component of all transition-focused education programs (Gil, 2007).

A review of seven Australian transition programmes for young people with disabilities moving to adult life highlighted that the concept of self-determination is increasingly influencing the structure and nature of transition programmes (Laragy, 2004). Others reported students who were more self-determined made significantly more advances in obtaining job benefits and earned more (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). Overall, research has found that students who are more self-determined often have better outcomes across multiple life categories, including, employment, access to health and other benefits, financial independence and independent living (Duvdevany, Ben-Zur, & Ambar, 2002; Wehmeyer & Palmer, 2003). Realisation of the importance of self-determination has resulted in policy changes and a greater focus on program development (Duvdevany et al., 2002).

#### 2.4.2.4 Employment, post secondary education and day options

The 'Major Life Areas' chapter within the activity and participation domain of the ICF describes work and employment as well as vocational training and higher education (World Health Organization, 2001). Employment options for youth with intellectual disability are described as open employment, supported employment, and sheltered workshops. The latter are segregated work settings for individuals with a disability. Some report that sheltered workshops provide interesting work in which individuals take pride and receive training geared towards progression to open employment (Gosling & Cotteril, 2000; Sandys, 2003), whereas critics argue that workshops are exploitive due to low rates of pay, irrespective of disability subsidies (Lemon & Lemon, 2003). The supports provided can be both formal supports and 'natural supports', the support of other co-workers and supervisors in helping to learn and maintain new skills (Mank, 1996; Mank, Cioffi, & Yovanoff, 2003; Wehman, & Revell, 1997). Issues with supported employment have been highlighted in some studies from the UK which report low satisfaction due to poor relationships with co-workers and high employer demands for productivity (Hyde, 1998). Another longitudinal study investigating adaptive skills conducted in the US, found that beneficial skills appear to be learned within integrative settings and lost within segregated work settings (Stephens, Collins, & Dodder, 2005). An important aspect of this research

(Stephens et al., 2005) was that although most participants were those with mild intellectual disability (~37%), there was adequate representation of all levels of intellectual impairment: moderate intellectual disability (~22%), severe intellectual disability (~16%) and profound intellectual disability (~20%).

Participation in supported employment has been reported to provide opportunities for independence and choice-making and has been associated with improved psychological wellbeing (Banks, Jahoda, Dagnan, Kemp, & Williams, 2010; Jahoda, Kemp, Riddell, & Banks, 2008; Wistow & Schneider, 2003). A systematic review of fifteen studies concluded that there were positive outcomes for people with intellectual disabilities entering employment specifically in terms of quality of life, wellbeing and autonomy. However limitations of this research included the difficulties associated with accounting for other inputs into autonomy such as way of learning, experience, supports, self-knowledge and confidence, and the failure to account for variables within different workplaces (Jahoda et al., 2008). Unemployment and being out of the workforce has been shown to negatively impact on an individual’s self-esteem, confidence, work attitude and feelings of adequacy, resulting in a negative psychological attitude (Roulstone & Barnes, 2005). Families of children with Down syndrome in Western Australia reported that for those engaged in paid employment, one third were not satisfied with their options. (Dyke et al., 2007). The key issues which were highlighted for this group included a limited number of hours available in open employment, together with long delays in being given the opportunity to try a particular placement (Dyke et al., 2007). A review of the issues and challenges associated with transition from school for youths with a disability focusing on the outcome of employment, highlighted that successful transition to employment is the responsibility of legislators and employers and educational authorities as well as the family of the person with the disability (Winn & Hay, 2009).

Individuals considered unable to engage in employment may participate in a range of ‘day services’. Day services vary but they usually involve a range of activities that aim to promote skill development, recreation, and community inclusion. Australian parents of young adults with intellectual disabilities have reported a lack of adequate full day adult services and called for increased funding for services in this area (Davies & Beamish, 2009) with this sentiment echoed in the UK (Brown, Shiraga, & Kessler, 2006; Kraemer & Blacher, 2001).

#### 2.4.2.5 Leisure

Leisure participation is reflected within the activity and participation domain of the ICF under the “Community, Social and Civic Life” chapter. Leisure participation for adolescents with intellectual disabilities has been associated with emotional and psychological benefits and has been found, by researchers in the US, to facilitate the development and generalisation of skills and adaptive behaviours across a variety of settings (Williams & Dattilo, 1997). It is recognised that leisure activities for young adults with intellectual disability typically involve a few stereotypical activities. These activities often include arts and crafts and bowling, and usually occur in a segregated setting or in the community with other individuals with a disability (Dattilo & Schlein, 1994; Hoge & Dattilo, 1995). Families in the US have expressed concern in relation to the lack of opportunity for their children to engage in integrated recreation activities, with concern increasing as youth transition from their childhood family and educational support services (Dattilo & Schlein, 1994; Hoge & Dattilo, 1995). Unlike typically developing youth, young people with intellectual disability do no adopt individualised patterns of recreation but appear to rely heavily on family recreation well into adulthood (Mactavish & Schleien, 2004).

Participation in leisure activities has been reported as similar across all levels of intellectual disability, mild to severe. Research from the US involving 490 young adults with disabilities suggested that high levels of engagement in leisure activities could be the result of parent run groups and recreational environments. These environments and networks are easily accessible and accepting of individuals with impairment. However, the researchers did not report on whether leisure activities occurred in segregated or integrated environments and they did not examine the role of choice in leisure activity participation (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006a). A pilot study in Israel involving young people with cerebral palsy with severe intellectual disability investigated whether virtual reality systems can provide positive and enjoyable experiences and potentially lead to increased self-esteem and a sense of self-empowerment (Weiss, Bialik, & Kizony, 2003). It was reported that the participants demonstrated a degree of enthusiasm during the virtual reality experience and some participants reacted to stimuli with appropriate goal-orientated responses (Weiss et al., 2003). The importance of participation in leisure activities has been highlighted by the finding from research in Hong Kong that limited participation in activities reduces opportunities for people with intellectual disabilities to realize they have control and choice over their lives (Li, Liu, Lok, & Lee, 2006). Choice is an important part of the transition to adult life and contributes to quality of life for young people with intellectual disability. Research in Ireland revealed that access to and location of leisure activities were common barriers to participation for young people with intellectual disabilities (Buttimer & Tierney, 2005). Further, fewer limitations in activities of daily living, educational attainment and the acquisition of adult social roles were significant predictors of participation in leisure activities of youth with a range of developmental disabilities, including a proportion who had mild (19%) and severe (13%) intellectual disability (Van Naarden Braun et al., 2006a). In cohorts of people with physical disabilities it has been found that greater involvement in leisure activities decreases stress, improves coping skills and adjustment to life (Specht, King, & Brown, 2002). However, there is a gap in knowledge in understanding this association among people with intellectual disabilities.

### 2.4.3 Personal factors

Personal factors are the particular background of an individual's life and living and may include gender, age, race, social and cultural factors, accommodation and geographical location (World Health Organization, 2001). Minimal research has examined the relationship between transition outcomes and various demographic and socio-cultural characteristics among people with intellectual disability. In a US study males tended to have higher rates of employment than females, as did white Americans compared to African Americans, youth from metropolitan versus rural areas and those from higher socio-economic compared to lower socio-economic areas (Harmon, Bender, Linden, & Robinson, 1998). Indigenous Australians who have a disability have been reported to have poorer employment outcomes than non-indigenous Australians with a disability. No specific research has investigated the transition process for Indigenous Australians or those from culturally and linguistically diverse backgrounds (Australian Institute of Health and Welfare., 2006).

The majority of young adults with intellectual disability live with their families well into their adult years (Duvdevany & Arar, 2004; Dyke et al., 2007; Esbensen, Seltzer, & Greenberg, 2007; Wehmeyer & Bolding, 2001). Ongoing demands of caring for a young adult with intellectual disability can place additional stresses on the family. Their need for alternative accommodation is increasing parallel to improvements in life expectancy (Kobe & Hammer, 1994). Recent research conducted in the UK found that almost three quarters of young people with intellectual disability who had left school were still living at home (Ward, Heslop, Mallett, & Simons, 2003). Although most parents wanted housing options to be included in the transition planning process, this had only occurred in 10% of cases (Ward et al., 2003). Where the young person had moved out of home it was primarily as a result of parents' efforts and financial resources (Ward et al., 2003). Other work in the US has found that 4% of young people with intellectual disability were living independently upon leaving school and this proportion grew to 24% after five years post-school transition (Blackorby & Wagner, 1996).

#### 2.4.3.1 Quality of life

Measuring quality of life as a transition outcome for young people with intellectual disability is an emerging concept. Quality of life as a transition outcome captures not only conventional outcomes such as employment, but also subjective aspects such as personal wellbeing, autonomy and self-determination (Kraemer, McIntyre, & Blacher, 2003). The concept of quality of life has been integrated into the ICF as a personal factor, operationalising aspects of the personal perception domain (Huber, Sillick, & Skarakis-Doyle, 2010).

Literature investigating quality of life in the US and New Zealand, as reported by parents as a transition outcome for youths with moderate to severe intellectual disability, found that the young people who had left school had a better quality of life than those still at school (Kober & Eggleton, 2005; Kraemer et al., 2003). Those in open employment were also more likely to have a better quality of life. It was suggested this may be due to parents associating leaving school with their child gaining greater independence and autonomy and non-school environments allowing for more choice making and autonomy. The study also identified adaptive behaviour as the strongest predictor of quality of life scores. Importantly however, other family factors were also found to significantly impact on these areas of quality of life; family coping styles, parents' involvement in the transition process, parents' knowledge of adult services, and parents' satisfaction with the amount of help they received from services during the transition period (Kraemer et al., 2003). Other research has highlighted the critical role families play in the wellbeing of individuals with intellectual disabilities during the transition period (McIntyre, Kraemer, Blacher, & Simmerman, 2004; Seltzer & Krauss, 2001). Thirty mothers of transition-aged young people with severe intellectual disability in the US were interviewed regarding their son's or daughter's quality of life. The discussions, in nearly three-quarters of the interviews mentioned recreation, activities and hobbies as important components of their young adult's quality of life (McIntyre et al., 2004). On the other hand, work (7%), communication abilities (10%) and health (13%) were rarely mentioned (McIntyre et al., 2004). The relationship between the various domains of the ICF and quality of life is an area requiring further exploration to highlight which life areas are most impacted.

### 2.4.4 Environmental factors

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors can either act as barriers or facilitators to an individual's functioning.

#### 2.4.4.1 Families

Families of young people with intellectual disability transitioning from school have compared this stressful and distinct phase of life to the time when their child was initially diagnosed (Hanley-Maxwell et al., 1995). Often the mismatch between the youth's physical size and adult maturation and their cognitive and functional abilities place families under increased pressure in relation to physically handling and managing behaviour which may be becoming more difficult to control and discipline (Read, 2000). However, family involvement continues to be considered an essential component of the transition process (Kohler & Field, 2003).

Transition tends to occur at a time when other important social changes are occurring within a family: the non-disabled siblings may be reaching young adulthood and leaving home; aging parents may mean the loss of an important source of informal support; and parents, more typically mothers, may find themselves in the dual caring role of supporting both their disabled young adult and aging parents. Grandparents and siblings of children and young people with Down syndrome have been reported as the two most common sources of informal support other than the spouse, highlighting the significant consequences of the family adjustments (Dyke et al., 2007). Additionally, these changes are occurring when, for most families, there is a sudden decrease in formal supports when their disabled adolescent leaves school (Knox, Parmenter, Atkinson, & Yazbeck, 2000). For some parents this reduction in formal supports may mean they have to cease employment or reduce their working hours to care for their young adult as well as assume the role of trying to co-ordinate services received from a number of different agencies (Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004). While this complex role of the parent emerges more from necessity rather than choice on the part of the parents it can have the potential to limit the development of the individual's own self-determination and choice making skills. These changes present both internal and external challenges to families trying to establish new routines that are compatible with a reasonable quality of life for all members, as reported in Australia (Schneider, Wedgewood, Llewellyn, & McConnell, 2006). Rather than the traditional measures used to measure the success of transition such as employment and independent living, it may be more pertinent to be considering using measures of family coping, wellbeing and quality of life (Schneider et al., 2006).

Parent involvement in transition planning is the most commonly cited predictor of a successful transition (Hendey & Pascall, 2002; Morris, 2002; Pownceby, Ratcliffe, Abbott, & Kent, 1997; Roizen, 2007). Individuals that appear to have the most success in achieving the transition are reported to have parents who are encouraging and supportive and have expectations that equate with achieving most aspects of adult life (Pascall & Hendey, 2004; Thomson, Ward, & Wishart, 1995). They are also likely to be prepared to advocate strongly on their young adult's behalf as well as fostering their independence. There is some evidence that supports the notion that parents who are able to provide this kind of support are relatively privileged in educational and economic terms and have the time, skills and money to fulfill the complex role required to support their young adult through the challenging and often prolonged transition period (Pascall & Hendey, 2004). Research investigating autonomy of young people with mild intellectual disability within the family unit, identified three approaches to reaching independence; defiant, passive and proactive (Mill, Mayes, & McConnell, 2009). These authors presented the point that transition to adulthood for people with intellectual disabilities is not inevitably conflict-ridden. Young person involvement in service decision-making and support from families to choose varied and valued roles and responsibilities within the family and community were shown to be important factors in reaching autonomy for these young people with mild intellectual disability (Mill et al., 2009).

Safety and risk have been described as major concerns for families during the transition period leading to parents being reported as over-protective. (Carr, 1994). This over-protectiveness may hinder an individual's development of social skills and choice making and can result in isolation and inactivity (Redmond, 1996; Smyth & McConkey, 2003). Although strategies to minimise this have been suggested (eg. 'shared risk strategy') in reality few service providers are adopting this approach (McConkey & Smyth, 2002).

#### 2.4.4.2 Services

A key factor in the important transition from school to post-school is navigating the bureaucratic aspects. This aspect of transition is unique to people with disabilities and for people with intellectual disabilities usually involves shifting from segregated settings and extra supports, social services and formal supports in mainstream education (Gillan & Coughlan, 2010). Transition services have been reported to have difficulties providing families and young adults with information about future options and opportunities (Heslop, Mallett, Simons, & Ward, 2002). Key elements of how this should be done have been identified but reports suggest that this information does not appear to be adequately reaching its target audience (Cameron & Murphy, 2002; Tarleton & Ward, 2005). Challenges accessing information will add barriers to a successful partnership between adolescents with intellectual disability and their families. Specifically it has been shown that young people with severe intellectual disability may have minimal or no involvement in transition planning processes (Davies & Beamish, 2009). A recurring theme amongst the limited evidence cited was the lack of options post-school (Kraemer & Blacher, 2001). Although it is generally thought that those with severe intellectual disability are unlikely to transition to any form of paid employment, they have been shown to be able to successfully participate in supported employment environments (Clegg et al., 2001). In a sample of 329 young adults, where 90% of participants had an intellectual disability, positive relationships with co-workers without a disability and work settings where co-workers had been trained in aspects of disability from supported employment personnel were key to this success (Mank, Cioffi, & Yovanoff, 1998).

Transitioning to adult health care services raises many issues for families and young people with an intellectual disability, including decreased access to co-ordinated services. Usually the young people are transferred to a general practitioner who may lack the knowledge to deal with the complexities of their disability and hence may refer them onto a number of different specialists, ultimately resulting in fragmented and uncoordinated care. A review in transition for adolescents with developmental disabilities involving young people with mild to severe intellectual disability, suggests that empirically based service models are required to manage transition from paediatric to adult health care settings. This review also highlights that some of these service models are in early stages of development (Betz, 2007).

#### 2.4.4.3 Transport

Transport is cited within ‘services, systems and policy’ within the environmental domain of the ICF. Lack of appropriate transport can have a significant impact on many activities including leisure, employment and making and sustaining friendships (Morris, 1999; Oates et al., 2009). Transport options can be influenced by a number of factors. These include parental concerns about a young adult's safety both in terms of capability and vulnerability to strangers, geographical location particularly in rural areas, and paucity of resources to assist with transport training. A study of the experiences of 283 families and young people with intellectual disability transitioning from school in England, found that only a third of young people who had left school had some level of transition planning which had transport options and/or training included in their plan (Ward et al., 2003).

#### 2.4.4.4 Policy and legislation

Legislation in the US has led many of the changes related to transition for young people with a disability in the developed world. The Individuals with Disabilities Act (IDEA) Amendments of 1997 embody a co-ordinated set of activities and outcomes designed to adequately ensure the preparation of students with disabilities for all aspects of adult life. Central to this legislation is the development of an Individualised Education Program (IEP) for each student that is annually updated. The IEP is described in Section 614 of the IDEA Amendments and is a plan which is designed with the young person and family at age 14, outlining the needed transition services (US Department of Education, 2006). Regardless of these efforts reports have described the transition process and post-school life in the US as somewhat negative. Low levels of participation in the transition process and poorly co-ordinated planning as well as high levels of unemployment, restricted participation in community activities and a continued dependence upon families (Gallivan-Fenlon, 1994; Keogh, Bernheimer, & Guthrie, 2004). Similar issues have been identified in populations within Australia (Burrows, Ford, & Bottroff, 2001; Murray, 2007) and the UK (Smart, 2004).

In the UK, the publication in 2001 of the White Paper, Valuing People, was a mandate for agencies working with people with disabilities to work in partnership to achieve better outcomes for individuals with disabilities. In support of these policy changes a number of service delivery initiatives related to transition have been developed in the UK. Regardless of these policy and legislation changes which identified some key underlying problems, transition remains difficult for young people with intellectual disability. The issues identified included the fact that transition was a low funding priority, planning is usually short term, there is organisational complexity, poor systemic coordination and a considerable gap between policy and implementation (Hudson, 2006).

In Australia, legislation related to transition has not been formally developed in the way it has in the US and the UK. However the Commonwealth/State Disability Agreement in 1991 reflected a policy shift to enhance the rights of individuals with a disability. The legislation included access to support services to obtain a reasonable quality of life; the right to individualised educational and developmental opportunities, and the right to exercise maximum control over every aspect of their life (Laragy, 2004). In Australia, the recent ‘welfare to work’ and ‘mutual obligations’ policies are the source of much debate and indecision as to whether such initiatives will act as barriers or facilitators for individuals with intellectual disability. These initiatives, like others in the US and UK, have created uncertainty for some around income entitlements, health benefits and employment choices for individuals with a disability. Central to these initiatives has been the creation of ‘transition co-ordinator positions’ considered to be critical to the success of the programs (Parmenter & Riches, 1991).

## 2.5 Conclusion

The range of issues related to transition from school to adult life for individuals with intellectual disability are complex and multi-faceted. Over the past two decades there have been many initiatives implemented within the developed world to try to facilitate a smooth and successful transition from secondary school, although very few have had positive outcomes in terms of fully participating in all areas of adult life. The ICF framework has allowed a structure by which some issues can be understood (World Health Organization, 2001). It allows the challenges and opportunities faced by young adults with intellectual disabilities leaving the school system to be viewed in a broader context than just the diagnosis and functioning levels of the individual. In particular it allows consideration of the impact of environmental and personal factors that may influence an individual's ability to participate in life activities (Wehmeyer & Garner, 2003). The use of the ICF provides a more integrative approach to gathering and sharing information with a universally understood language. Pilnick and colleagues (2011) highlighted that the mainstream psychological literature in intellectual disability has attempted to describe and account for conduct by people with intellectual disability according to individual characteristics rather than contextual influences (Pilnick, Clegg, Murphy, & Almack, 2011). Others have adopted the stance that intellectual disability is largely a social construct (Rapley, 2004). More recently, it has been argued that intellectual disability is more than a social construct (Pilnick et al., 2011). The ICF provides a holistic framework to capture all of these domains. This framework has been used successfully not only as a framework for reviews (Geyh, Cieza, Kolleritis, Grimby, & Stucki, 2007), but also to evaluate outcome measures and their utility (Sakzewski, Boyd, & Ziviani, 2007; Swanson, Carrothers, & Mulhorn, 2003). It has been used in governmental departments in developed and developing countries (Kennedy, 2002; Madden, Choi, & Sykes, 2003; Mbogoni, 2003) and for classifications of particular disorders (Arthanat, Nochajski, & Stone, 2004; Battaglia et al., 2004; Rosenbaum & Stewart, 2004). However, until now, the use of the ICF as a guiding framework has been omitted from the area of transition for young people with intellectual disabilities. In the context of this review, the ICF has highlighted the importance of environmental factors including family systems, post-school services and access to transport as specific areas for consideration during the transition from school to post-school for young people with intellectual disabilities. Policies, services, personal characteristics and the family, the importance of which is being shown by emerging evidence, can be key facilitators or barriers to participation outcomes (Kohler & Field, 2003; Schneider et al., 2006).

This review has highlighted significant gaps and weaknesses within the literature investigating transition from school to post-school for young people with intellectual disability. Research which involves the young people themselves is sparse and usually only involves those young people who have mild intellectual disability (Butcher & Wilton, 2008). Additionally, research has tended to focus on only one aspect of transition (eg. employment or transition of health services) as opposed to taking a more holistic view of outcomes (Beresford, 2004). A recent review investigating the issues and challenges related to transition from school to post-school for youths with disability, used employment as their primary outcome. The authors briefly mention friendships and the role of work as being more than about income and productivity, yet they neglected to explore the value and importance of concepts of participation, and environmental and personal factors which impact the transition (Winn & Hay, 2009). To our knowledge, there is no research from low and middle income countries (LAMIC) regarding transition from school to post-school for youth with intellectual disabilities. This reveals a gap in the literature which future research needs to address. Other limitations include the difficulty in viewing outcomes such as quality of life or autonomy as a closed system with single causal factors (Jahoda et al., 2008). Failure to take into account workplace factors when investigating supported employment outcomes is another common limitation in transition literature for young people with intellectual disabilities (Jahoda et al., 2008).

The transition process has been shown to be associated with substantial disruptions to family routines and responsibilities (Davies & Beamish, 2009). Family involvement continues to be considered an essential component of the transition process (Kohler

& Field, 2003). Their experiences provide information of strong practical value to improve services, highlighting the importance for service providers to understand family belief systems. This has been reported as imperative to developing an effective working relationship with families and therefore implementation of effective service delivery (King, Currie, Smith, Servais, & McDougall, 2007; Schneider et al., 2006). The overall picture indicates that policy and legislation adjustment as well as transition programmes and the development of resources has so far had little impact on improving the transition experience from school to post-school for young people with intellectual disabilities. It is imperative that future researchers acknowledge the challenges and issues with current research and amends research designs to close the gaps in the current knowledge base.

## Preface to chapter three

Chapter three of this thesis describes a qualitative study with children and young people with disabilities. This study aimed to describe the perspectives of the young people with disabilities about the meaning of wellbeing. Understanding the meaning of wellbeing from the perspective of children and young people with disabilities is important in underpinning policy and service delivery and was used to guide the thesis. The concept of participation, a key concept in this thesis, is fluid and multi-faceted. The voices of children and young people with disabilities within chapter three, plays a key role in defining the influence which participation has on wellbeing and also highlights the invaluable contribution children and young people with disabilities can make as active participants in research. This study was published in *Child Indicators Research* in 2012. The full, published manuscript is provided as Appendix G.

The PhD Candidate, Kitty-Rose Foley accounted for 85% of the intellectual property associated with the final manuscript. Collectively, the remaining authors contributed 15 per cent.

# Chapter 3: Perceptions of children and youth with disabilities

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## TO FEEL BELONGED: THE VOICES OF CHILDREN AND YOUTH WITH DISABILITIES ON THE MEANING OF WELLBEING

### 3.1 Abstract

Purpose: The aim of this paper was to describe the meaning of wellbeing for children and youth with disabilities from their perspective.

Method: Twenty children and young people with a range of disabilities including, cerebral palsy, autism, Aspergers syndrome, Down syndrome, mild to moderate intellectual disability and vision impairment, participated in six focus groups. Groups were facilitated by at least two experienced professionals, including one scribe who recorded the discussions within the groups and took field notes on contextual information. Open coding was used to initially name and categorise data. Constant comparison methods were then used to compare codes and categories to advance the conceptual understanding.

Results: Six themes of the meaning of wellbeing emerged from the data describing, ‘having things to do’ (participation), ‘the importance of good friends’ (relationships), ‘home is where the heart is’ (family factors), ‘nothing seems to stick in my brain’ (anxiety relating to performance at school), ‘you need some way to cool down’ (coping strategies/resilience) and ‘feeling good about yourself’ (personal growth and development). The concept of wellbeing from the child’s and young person’s perspective was described as feeling supported, included and respected, as well as feeling valued and capable.

Conclusions: Ideas raised by children and young people have highlighted gaps within current indicator sets of children’s wellbeing. These include reciprocal respect within relationships, coping strategies, feeling valued and having a positive sense of self.

Children and young people can provide valuable input into research, regardless of impairment.

## 3.2 Introduction

It is estimated that people with disabilities make up 10% of the world's population (United Nations, 2006). In Australia, which has a broad definition of disability, the prevalence of people with disabilities is approximately 20%, and children with disabilities around 8.3% of those aged 0-14 years (Australian Institute of Health and Welfare, 2008). In 1998, 144,100 Australian children aged 0–14 years (or 3.7% of the population of this age) were estimated to have a physical/diverse disability, either as a main disabling condition or an associated disabling condition (Australian Institute of Health and Welfare, 2004). The next most common disability group among children was intellectual/learning disability (143,000 children or 3.7% of the population of this age), followed by sensory/speech disability (119,900 or 3.1%), psychiatric disability (43,600 or 1.1%) and disability related to acquired brain injury (12,700 or 0.3%). Evidence shows that children with disabilities often have poorer outcomes compared to their non-disabled peers, in a number of areas including material wellbeing, health and safety, education, and emotional wellbeing (Allen, 2008; Anderson, Dumont, Jacobs, & Azzaria, 2007; Australian Institute of Health and Welfare, 2004; De, Small, & Baur, 2008; Decoufle & Autry, 2002; Emerson, Honey, & Llewellyn, 2008; Richman, 2008; Sullivan & Knutson, 2000; Williams et al., 2005).

In 1990 the United Nations ratified the "Convention on the Rights of the Child" (CRC) thereby focusing on the responsibility of states to ensure children's safety and wellbeing (United Nations High Commissioner for Refugees, 1989). While the Convention briefly touched on the special needs of children with disabilities it was only in 2006 that a specific convention on the Rights of Persons with Disabilities (CRPD) was adopted by the United Nations (United Nations High Commissioner for Refugees, 2006). This Convention shifted the paradigm from viewing people with disabilities as recipients of medical treatment and in need of protection against discrimination, to individuals with their own rights capable of making decisions and being active members of society.

Following the ratification of the CRC a number of reports including the “State of the World’s Children” (United Nations Children's Fund (UNICEF). 2011), “Child Poverty in Perspective” (United Nations Children's Fund (UNICEF). 2007) and in Australia “A Picture of Australia’s Children” (Australian Institute of Health and Welfare., 2009) measured the progress of countries against specific indicators of children’s health and wellbeing. Presence of disability has been used as a measure of poor outcomes for children. However, there has been little focus on wellbeing within this population. Currently, there is a lack of research on what indicators of health and wellbeing are appropriate to use for children with disabilities and there are very few studies that have asked children with disabilities what they view as important for their own wellbeing (Huebner, Brantley, Nagle, & Valois, 2002; Llewellyn & Leonard, 2010). This information is essential for the design and implementation of strategies to maintain and improve wellbeing in this population and also for the assessment of the success of these strategies.

A challenge associated with undertaking research in this area is that children’s views will be dependent on a number of factors including type of disability, age and level of functioning (Australian Institute of Health and Welfare, 2009; Hanafin & Brooks, 2009). The aim of this paper was to describe the meaning of wellbeing for children and youth with disabilities from their perspective.

## 3.3 Methodology

A generic qualitative research approach was taken for this study with focus groups considered the most appropriate data collection strategy (Caelli, Ray & Mill, 2003). The presence of peers was thought to help minimise participant stress and provide a forum for the participants to brainstorm together. They provide an efficient method of assisting the collection of rich data at low cost (Flick, 1998). Conducting focus groups with groups of marginalised populations has been found to be particularly useful in previous research (Lorig, 2001; Tietelman & Copolillo, 2005).

### 3.3.1 Sample

A purposive sample (participants selected according to the needs of the study) was recruited from a variety of sources (Patton, 1990). A number of disability service providers and schools were contacted to gauge interest in involvement in the study. The organisations and schools then made contact with families of potential participants and invited them to participate in the study. Families of the children were provided with an information sheet and were advised of the purpose of the study, what data would be collected and the use of research data upon completion of the study. Informed consent was obtained from the parents and guardians of the participants. Written consent from the children was gained in some cases; otherwise the children and youth provided verbal assent to participate. The research protocol was approved by the Human Research Ethics Committee of the University of Western Australia.

### 3.3.2 Data collection

The groups were facilitated by three different experts who had training and experience with interviewing skills and working with children with disabilities. At least two facilitators were present at each group (including one scribe) and often a classroom teacher and/or education assistants. The scribe recorded the discussions within the groups and also took field notes on environmental factors, non-verbal cues and other contextual information. A permissive environment which allowed the participants to feel safe and comfortable in volunteering their opinions and ideas was created (Kreuger, 1994). It is important to ensure that research with children and young people involves simple, straightforward and easy to understand questions and foci (Bryony Beresford, 1997; NSW Commission for Children and Young People, 2005). Thus the primary questions underpinning the focus groups were “What is important for a good life?” and “What are the barriers (or what gets in the way) of having a good life?" Data collection methods included group and one-on-one discussions, group brainstorming, drawing pictures with colourful textas and writing lists on large pieces of butcher's paper.

Conducting qualitative research with children with physical and intellectual disabilities is challenging with few examples in published research (Booth & Booth, 1996; Lloyd, Gatherer, & Kalsy, 2006; Swain, Heyman, & Gillman, 1998). Within these focus groups open questioning, rephrasing of questions and verbal and physical prompts were strategies used to encourage the participants to provide their responses and thoughts. In addition, participants were encouraged to write down and/or draw their thoughts and feelings concerning the topics raised. Although additional groups may have produced additional description of themes, six groups were sufficient to gain an in-depth description with data saturation achieved.

### 3.3.3 Data analysis

The data provided by the six groups were analysed by a researcher who had not been involved in collecting the data. Groups were audiotaped and transcribed verbatim at a later date by the scribe. Scribes notes were also available for analysis. An open coding method was used to name and categorise the data (Strauss & Corbin, 1990). Constant comparison methods were used throughout the coding and analysis of the data (Charmaz, 2006). Codes were then categorised into broader categories that emerged to form the major themes (Crotty, 1996). Credibility of the findings was further enhanced by a review of the coding by an expert in the field of qualitative research and another external researcher conducting a separate analysis using the same protocol (Mays & Pope, 1995). Member checking with participants from two of the focus groups occurred prior to finalisation of interpretation of results.

Research strategies and choices made in a generic study are still informed by a set of assumptions, preconceptions and beliefs (Caelli, Ray & Mill, 2003). This study was undertaken in collaboration with service providers who work in government and non-government sectors with children and families with disabilities. Therefore, all researchers involved in this study would have preconceived opinions on what contributes to the meaning of wellbeing for children and young people with disabilities. Additionally, at the time of writing this chapter the author (the PhD candidate) was working clinically as an Occupational Therapist with children with disabilities. Experiences through clinical work had the potential to influence interpretation of these data due to assumptions and an already established beliefs system. The influence of personal experience on interpretation of results was minimised by a review of coding by an external qualitative expert and through personal reflections during analysis (Mays & Pope, 1995; Di Cicco-Bloom, & Crabtree, 2006). These considerations help to ensure the presentation of a rigorous and thoughtful study (Caelli, Ray & Mill, 2003).

## 3.4 Results

### 3.4.1 Participant characteristics

Nine girls and eleven boys aged 8 to 16 years old with a range of disabilities participated in focus groups. Three children had Down syndrome, seven autism spectrum disorder/Aspergers syndrome, six cerebral palsy, one a vision impairment and three had an intellectual disability for which the cause was unknown. The focus groups lasted from one to three hours in length and took place in a variety of settings. One focus group took place in a private therapy practice, three in a classroom and two at The Centre for Cerebral Palsy. Pseudonyms are used to refer to the children in this paper.

### 3.4.2 Theme one: “Having things to do”

Participating in different activities was the most frequent topic of discussion in all focus groups. The children discussed participating in recreational activities, including dancing, bowling, volleyball, ballet, swimming, visiting the beach, attending concerts, playing sport, riding bikes, playing with friends, going to the movies, listening to music, listening to the radio and computer games; educational activities such as completing assignments, and homework; and social activities such as playing with friends, being in groups with friends, and spending time with friends.

Patterns in the data revealed that the children valued participation in personally meaningful activities. Mary a sixteen-year-old with Aspergers syndrome described why she enjoyed drama: *“Not so much sport, it’s not my thing. I do more drama... the thing I like about drama is getting to know people more, especially the comedy, that can be fun.”* Nick, a fifteen-year-old boy with high functioning autism discussed how he felt about drawing *“I like just getting creative behind it, and expressing my feelings.”* These comments highlight the importance that these children and youth place on participation in these activities. The idea of being in control of decisions surrounding participation also emerged in the discussions. Edward, an eleven year old boy with moderate intellectual disability described *“playing playstation two and getting more games – and getting to play them whenever you want.”* Lincoln, a twelve-year-old with cerebral palsy also commented on how important being in control of an activity ensuring it is meaningful for him was: *“You have the right to do what you want and choose between things… like choose where you want to go for a birthday party, what clothes you wear.”* It could be argued that these statements reflect the children’s desire to be self-determined. Research with people with intellectual disabilities suggested focusing intervention on facilitating development of skills which could increase self-determination and therefore foster healthy development and functioning (Shaddock, Bond, Bowen, & Hales, 2000; Laragy, 2004).

The International classification of functioning, disability and health (ICF) describes participation as ‘involvement in life situations’ and does not discriminate between activity and participation in its coding. Harriet, a fifteen-year-old girl with Down syndrome reflected this ‘involvement” when she said *“to feel belonged,”* not only referring to carrying out an activity but truly feeling a part of something. The original ICF (World Health Organization, 2001) drew attention to the importance of considering the activities and participation of adults with disabilities, and not merely body functions and structures. The Children and Youth version (World Health Organization, 2007) extended this perspective into the younger age ranges. The present study indicates that this emphasis on activities and participation is consistent with the world views of children with disabilities themselves. When questioned as to what makes a good life the children in this study did not talk about their bodily impairments and limitations, but of joining in with friends and family and having personally meaningful things to do. Research has demonstrated that participation doesn’t necessarily depend upon level of impairment, and that children with similar levels of impairment experience diverse levels of participation and quality of life (Colver, 2006).

The restricting influence that environmental factors can have on social participation may parallel the restricting influence that personal characteristics can have on participation for people with a disability (Fougeyrollas, Noreau, & Boschen, 2002). In this study the impact of the environment on social participation emerged from the children’s comments about the need to adapt activities to accommodate them or choose activities that would suit them. Ben, a ten-year-old with vision impairment discussed being involved in sport and playing music: “*You can’t play many sports like you can’t play cricket or tennis because the ball is too small for me with my vision, but they aren’t the only sports out there…I can still play music I just need the notes enlarged. I play the piano.”* Attitudinal environment can also have an impact on participation, Ben commented on the negative impacts of social attitudes *“people that just expect you to do things really. I mean most people are really great but there are some people who aren’t... people who pretend there is nothing wrong with you and tell you to do this, and do that… people who think they are better than* *me because I have a sight problem."* In response to the question 'what gets in the way of a good life' Emma a sixteen year-old-girl with Down syndrome said *"other people telling me things"* and Jackie a thirteen-year-old with cerebral palsy said *"people stopping you doing what you want – if they just say no or don't."* The United Nations Convention of the Rights of Person with Disabilities states 'to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, transportation, information and communication' (United Nations, 2006). Research has highlighted that this is not always the reality for people with disabilities and that this is a goal towards which all countries must continue to work (Vik, Nygard, & Lilja, 2007). However, the recognition of the importance of the environment in the interaction between human development and disability is a fundamental shift in paradigm which has the potential to positively impact on the participation of people with disabilities (Fougeyrollas et al., 2002).

### 3.4.3 Theme two: *"The most important thing is good friends"*

The importance of friendships in a good life emerged from discussions within the focus groups. In response to the question: "What would be important for a good life?" Nick, a boy with autism spectrum disorder, responded, *"for starters, mine would be good friends."* When asked about her favourite things to do, Harriet, a fifteen-year-old girl with Down syndrome, stated that *"the most important is good friends."* Ben, a ten-year-old with vision impairment, discussed the value he placed on the quality of friendships, rather than the quantity: *"Having close friends rather than just lots of not close friends."* Ben also explained how he would often spend his social time with adults when he was not able to participate in activities with his peers: *"Sometimes kids might be playing sports and I just go talk to the adults…they usually talk about restaurants and stuff…I've been to lots of restaurants as well so I can have an opinion about them."*

Friends were described as providing a sense of belonging and acceptance, assistance with personal matters, support in decision-making and sources of information. They engaged in activities together and shared things with each other. Making friends and being included with friends were mentioned as an integral part of school life. Friends who proved to be unkind (e.g., teasing them about their disability) or unreliable (e.g. betraying secrets *"My unfriendly Josh, I told him to keep this secret (and he didn't)"*) were cited as barriers to a good life. Research has identified that for young people with disabilities a central barrier to experiencing friendships is a lack of independence. This lack of independence has often been attributed to geographical, practical and safety issues (Cuckle & Wilson, 2002). This highlights the impact that environmental factors can have on participation in friendships for young people with disabilities. However, environmental factors were mentioned minimally in this research. This could be attributed to the fact that the children and young people within these focus groups lived within close proximity of one another and in most cases attended the same school. The emphasis which young people and adults with disabilities place on friendships has been widely reported although some young people with intellectual disability may have few friends (Oates et al., 2009).

### 3.4.4 Theme three: "You know home is where the heart is"

Rachel, a sixteen-year-old with Down syndrome stated that *"it's hard at home."* Mary, a sixteen-year-old with Aspergers syndrome highlighted the positive aspects: *"I think you need to have a family to have a happy life yourself… sometimes they're not good families, but I'm drawing a nice family here."* Some of the children who came from families where their parents had separated discussed spending time with each parent individually. In response to 'what makes a good life?' Edward, an eleven-year-old boy with moderate intellectual disability, said *"spending time with Daddy… going to Daddy's house."* Harriet, a sixteen-year-old with Down syndrome, mentioned *"going shopping with Mum."* Home was also described by some children as a safe place where they felt emotionally secure, Lincoln stated *"at home children are kind to you, they behave."* The influence of family factors on every child's wellbeing and health is well known, yet little research has examined this from the child’s or young person’s perspective especially when the child or young person has a disability.

The comments regarding families from the group discussions often made reference to siblings. Sibling relationships play a central role in development, modelling of behaviours and opportunities for play and social interactions (Noller, 2005). Sibling relationships involving a child with a disability have been found to be similar to those of typically developing children and in some cases of children with Down syndrome a more positive relationship has been reported (Cuskelly & Gunn, 2003). Participants in these groups described their siblings with respect. For example, Alistair, who has high functioning autism, commented in regard to his older sister *“she has a tendency to be very clever, and she helps me prepare for things. She’s really modest too.”* Daniel, another boy with high functioning autism who was present in the same group as Alistair had a twin sister *“I have a twin Sister, she goes to xx high school. She really hates tomatoes, but likes tomato sauce.”* Daniel went on to explain that he got to eat her tomatoes which was positive for him. Ben, a ten-year-old boy with vision impairment described the relationship he has with his brother: *“My Brother helps me out, and when he has friends over I play with them, and when I have friends over [my brother] plays with them.”* Frustrations and annoying experiences with siblings were also discussed in response to the question what ‘gets in the way’ of leading a good life. For example, Max, who had high functioning autism, described *“being annoyed by Brothers and Sisters.”*

### 3.4.5 Theme four: “Nothing seems to stick in my brain”

The young people with an intellectual disability in our groups expressed anxieties linked with underperforming academically. Children who did not have an intellectual disability also discussed their anxieties relating to performance at school. Little is known about the stress, worry and anxiety which may accompany these experiences and how they may impact on other areas of life such as behaviour, attention, self-worth and wellbeing (Buckley, Bird, Sacks, & Archer, 2006). However, there are known links within other populations between education attainment and wellbeing (Ansari & Stock, 2010).

Alistair, a fourteen-year-old boy with high functioning autism commented about his experience of school *"I worry about getting everything done."* This comment was met with much consensus from the other six members of the group. Daniel, another fourteen-year-old boy with autism spectrum disorder added *"I wish we could do everything at school and then just go home."* Mary, a sixteen-year-old girl with Aspergers syndrome explained: *"I really don't like tests and exams. Especially because when there's lots going on at school, I generally focus on the test but nothing seems to stick in my brain."* Children with high functioning autism have also been found to experience higher levels of anxiety when compared both with children with specific language impairment and typically developing children (Gillot, Furniss, & Walter, 2001). These findings highlight the importance of managing this anxiety in a school context to ensure children and young people with high functioning autism are supported to attend to classroom activities and have adequate opportunities to learn. It is widely accepted in typically developing populations, that there is a strong link between health and wellbeing as essential elements for effective learning, further highlighting the importance of this theme (Novello, Degraw & Kleinman, 1992).

Amber, an eleven-year-old with cerebral palsy explained her concern with repeating work *"having to do things again that you don't want to do, like homework if you rush it the first time and get it wrong."* In this same group, Lincoln who also had cerebral palsy mentioned *"not doing your homework (means) marks go down… get into trouble."* These particular participants, who did not have an intellectual disability, were able to identify the importance of school which, in turn, played a role in heightening their sense of anxiety. These children clearly understood the long term impact of not doing well at school, as Jackie said *"getting good marks at school so you can go to uni and have a good life, get a good job."*

Qualitative research involving typically developing children, which explored what constitutes wellbeing and what meaning children ascribe to it, identified three main themes: a positive sense of self, a sense of agency and feelings of security (Fattore, Mason, & Watson, 2009). Fattore and colleagues (2009) concluded that children understood that rewards in the context of education were provided to those who did well, and that their that feelings of self-worth were anchored in experiences of positive recognition, particularly in the educational context. The children and young people participating in the present study identified under-performance at school as an area which *'gets in the way of leading a happy life.'* Children and young people with disabilities, specifically intellectual disabilities, perform more poorly at school in comparison with their non-disabled peers (Turner & Alborz, 2003). This fact could contribute to the school environment acting as a barrier for young people with disabilities experiencing positive wellbeing. However, school has also been identified as the main source of opportunity for social interaction with typically developing peers and with peers with Down syndrome (Oates et al., 2009).

The children raised discussion pertaining to involvement within mainstream schools. For example, Ben, the 10-year-old boy with vision impairment spoke of being involved in sporting games with his typically developing peers, *"for cricket I use one of the bigger soft bouncy balls that are good for hitting… everyone there knows about (my vision impairment) and we just use the bigger ball and I don't think anyone minds."* Max a thirteen-year-boy with high functioning autism, who attended a mainstream school, mentioned how he learnt from his typically developing peers *"If you have friends, you can learn things about them… they might get you interested in other things."* Mirroring other children is a technique used by typically developing children during development to learn new skills and behaviours

(Nielson, 2006). Inclusive education provides this opportunity during everyday activities. Issues in segregated schooling include lower academic expectations, the fact that children with disabilities are removed from their communities everyday to attend school as well as social attitudes which did not allow children with disabilities into clubs and activities in their communities (Buckley et al., 2006). Inclusion of children with disabilities in mainstream schools needs to be carefully managed to ensure that it is not a negative experience for students and that there is positive acknowledgement and recognition of progress and achievement.

### 3.4.6 Theme five: "You need some way to cool down"

A theme of resilience emerged throughout the data in the form of coping strategies and hardiness described in the face of bullying or negative experiences. The explanations were quite specific to the situations of the participants, yet an overarching theme of resilience was identifiable across the groups.

A few of the children recognised that their quality of life would depend on what they made of their life, not merely what happened to them. They appreciated that they had a responsibility to be active in managing their lives, developing life skills, striving towards their goals, and coping with problems. For example, Ben, the 10-year-old boy with vision impairment commented: *"A good life is basically like you can't be always sad about it, it's alright but just look on the brighter side"*

A recurrent theme of his interview was how to make the best of life. Ben was well aware of many things that he couldn't do (e.g., play cricket or tennis, drive a car, become a surgeon), but he repeatedly turned it into something positive *"I think about things I can be and can't be, my friends and I have a joke about if I was a doctor or a surgeon... You can have a laugh about it."* When he was prevented by his disability from doing one activity, he would find another or make it into a joke or reflect on how little it really mattered. He refused to let anything get him down, and his buoyancy and optimism were the secret of his view of a good life. He commented *"the Doctor said, if my sight doesn't get any better I can't drive a car but it's not the end of the world."*

Parallels between comments from the children and young people in these groups and those of typically developing children who were interviewed about their wellbeing were evident (Fattore et al., 2009). For example, a typically developing 14-year-old female, highlighted the importance of having time on her own to make her feel good. *"I think giving yourself time to think and process everything that is going on around you"* (pg. 64)(Fattore et al., 2009). Similarly, Sam, a twelve year-old-boy with cerebral palsy, explained how he dealt with his emotions and valued time alone for reflection *"its good to go to your room and just lie down on your bed and cool down if you're feeling really angry with someone or yourself."*

In Australia approximately one third of children and young people who attend school have been reported to be victimised by bullying every week (Australian Institute of Health and Wellbeing, 2011). It has been reported that children with learning disabilities who have poor social skills and are excluded by their peers are more likely to become victims of bullying (Flynt & Morton, 2004). The children in this research mentioned episodes of bullying that they had experienced. Lincoln, a twelve-year-old with cerebral palsy, commented, *"they want to make themselves feel good so they put other people down, they put you down all day and say mean stuff to you, make you feel left out."* Jackie, a thirteen-year-old with cerebral palsy, said *"[bullying] makes you feel small, you want to do the right thing but people are ganging up on you to do something you think is not right."* Bullying or peer victimization can have detrimental effects on an individual. It can lead to greater depression (Austin & Joseph, 1996), lower self-esteem and self-worth (Andreou, 2000; Piek, Barrett, Allen, & Louise, 2005), and the victims can experience lower levels of happiness (Rigby & Slee, 1992). Service providers need to be aware of the prevalence of bullying amongst young people with disabilities and implement strategies to help these children identify and speak about bullying and teach them coping strategies to deal with negative social experiences.

### 3.4.7 Theme six: "Feeling good about yourself"

Personal growth and development were discussed within some of the groups, including discussion of goal-setting, striving to do their best, not wanting others to under-estimate them and facing their fears. Nick, a fifteen-year-old boy with high functioning autism, said*"I want to help others in their lives that are a bit less fortunate, give back to other people what they gave to me… not just about other people helping you."* The children and youth wanted to feel that that they were not merely passive recipients of disability services, but that they would have the skills to occupy a valued role in society.

Ultimately, quality of life is a subjective judgment. People have a good quality of life when they themselves judge it to be good and a poor quality of life when they themselves judge it to be poor. The children in this study acknowledged that their views of themselves were critical to their quality of life. Therefore, some children mentioned the importance of their own behaviour in having a good life. When they knew that they were behaving well, they felt good about themselves. Amber, an eleven-year-old girl with cerebral palsy, spoke about honesty*"[Being honest] makes you feel good inside that you've told the truth."* Similarly, Ella, a 10 year old with autism and mild intellectual disability discussed the importance of working hard, "*It makes you feel better when you're working hard – having no pegs on your traffic lights."* Peer pressure to behave in ways that the children and youth did not consider appropriate set up an uncomfortable cognitive dissonance for some, and they would rather resist the peer pressure than feel ashamed of themselves as Jackie explained *"When other people want you to do things that you think is not right… [it] makes you feel small.. you want to do the right thing but people are ganging up on you to do something you think is not right… [I] can tell the teacher, being honest."*

During a discussion with the facilitator about ‘things that are important to leading a good life,’ Harry, an eight-year-old boy with cerebral palsy, said *“the way you look,”* after further prompts about why, Harry explained *“because I don’t care that I have tight muscles.”* The issue of body image emerged again in a different group. Harriet, a fifteen-year-old girl with Down syndrome, explained the importance of *“feeling good about yourself and then when you look at yourself in the mirror you feel sad and upset and you want to do something about it.”* These feelings and comments, regarding body image and physical attractiveness, mirror the feelings of typically developing adolescent females in the general population. Although, as young adults with Down syndrome have specifically identifiable facial features (Roizen & Patterson, 2003), these anxious feelings about body image may be heightened within these young people. Perhaps education and awareness within the mainstream population regarding physical differences which people with disabilities experience could assist in minimizing these prejudices.

### 3.5 Discussion and conclusion

The children and young people’s comments about the factors that contributed to their wellbeing or detracted from it, revealed what was included in their own personal ideas of wellbeing. The above six themes can be further conceptualized into an overall picture of wellbeing from the young person’s perspective. For the participants in this study, "wellbeing" included feelings of being supported, of being included and respected, of being viewed as valued and capable, and of having feelings of self-respect and self-esteem.

The value that these children and young people placed on their friends and family partly derived from their need to feel supported (they *“encourage you… can help you… support you when you make a decision”; “they bring peace to people”)* and partly from their need to feel included and respected (*“you feel belonged”; “friends… that… know that they like you and you like them”*), whereas their concern about bullies, was because “*they make you feel left out*”. Feeling valued and capable was also included in the concept of wellbeing. This was illustrated by the need to have *“something to go for, strive for”*, by a child’s distress when people *“underestimate what I can do”* or *“think they’re better than me”*, by a child’s desire *“to help others in their lives that are a bit less fortunate, give back to other people what they gave to me… not just about other people helping you”*, and by a child’s pleasure when he *“faced fears”* and *“did things I’d never done before”*. Self-respect and self-esteem were also included in wellbeing for these children, as shown by comments about *“feeling good about yourself”* (i.e. body image) and about your own behaviour *(“makes you feel good inside that you’ve told the truth”*).

Findings from these focus groups highlight the overall importance children and young people with disabilities place on participation. In describing participation, the children and youth went beyond simply doing the activity and they highlighted the need to ‘feel belonged.’ Feeling involved and taking a useful role in activities and situations was continually referred to within all of the groups across disability types. Confirming the meaningful role that ‘being involved’ has for children and youth with disabilities from the young person’s perspectives goes a long way to validating the paradigm shift that is moving rehabilitation towards participation rather than focusing solely on impairment. The United Nations indicated over a decade ago that enabling participation should be one of the primary aims of rehabilitation services nationally and internationally (United Nations, 1994). However, a decade later, the question remains as to the extent that participation is enabled for people with disabilities. An issue with current research which attempts to measure participation is the strong focus on activity rather than on involvement, and the improvised nature of measurement of participation found within current research (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009a). A review of current participation measures would be useful in clarifying the most useful validated measures to measure participation by children and young people with disabilities.

Within the discussions in the focus groups in this study, there was little conversation concerning medical conditions, hospital visits or doctors/therapy appointments. It seems, contrary to the current medical model employed by many services, that these factors contributed minimally to the children's and young people's views on wellbeing. The impact of environmental factors on participation and quality of life has recently being identified as a major barrier (Colver, 2006; Colver et al., 2010). Societal and cultural contexts have also been found to have an impact on wellbeing (Bennett & Lu, 2007). This study has highlighted some of those circumstances where environmental factors 'got in the way' of leading a good life (eg. the size of the ball during sporting games, attitudes and expectations of people around them). It is important to consider the specific experiences for each individual when reflecting on wellbeing. However, there is also great value in appraising wellbeing across children and young people with different impairments to gain a true reflection of the range of factors impacting on these young people's lives. The characteristics of the disabling condition, along with child and family factors and informal supports from the community, are all likely to have an impact on the outcomes for the young person (Patterson & Blum, 1996). The creation of environments where children can optimally develop is a vital consideration (Patterson & Blum, 1996). Service provision should give serious consideration to adjusting environmental characteristics and providing education to the wider community in order to have the most beneficial impact on the wellbeing of children and youth with disabilities.

A report entitled "*Child indicators of wellbeing and children with disabilities: mapping the terrains*" (available at http://www.aracy.org.au/publicationDocuments/Indicators_of_health_and_wellbeing_for_children_with_disabilities.pdf) highlighted the limited research examining how children and young people with disabilities experience and understand wellbeing (Llewellyn & Leonard, 2010). The authors presented a comprehensive set of child indicators of wellbeing for children with disabilities developed from the UN

Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. Our research aimed to find out, from the perspective of children with a disability, what they see as important factors which contribute to, and act as barriers preventing their own wellbeing. Not surprisingly, many of the factors the children raised were reflected well within the set of wellbeing indicators developed from the UN Conventions. For example, the key themes of identity, parents and family, participation, dignity, education, development, environment and independence could be directly mapped to a number of the participant's comments (Table 4). However, there were a number of ideas and factors raised by the children which were not reflected within the wellbeing indicators set developed in the above report. The present research adds to these indicators from the children and young people's own perspective on their wellbeing.

There were a number of indicators drawn from this research that could be added to the wellbeing indicator set presented within the 'Mapping terrains' report (Llewellyn & Leonard, 2010). Children and young people were shown to value having the opportunity to receive respect and show respect, in the form of *'helping others'*. The reciprocal nature of these relationships was an element not previously addressed within the wellbeing indicator set. Importance of coping strategies and how these helped the children and young people lead 'good lives' was also discussed within this study although not apparent within the indicator set. Additionally, having the opportunity to feel valued and useful, body image and self-esteem were highlighted as factors influencing the children's and young people's wellbeing. These indicators could be considered within an overarching theme of autonomy. Autonomy refers to being 'self-governing' and differs from independence as it goes beyond 'acting independently of adults and carers' (Llewellyn & Leonard, 2010). Making decisions, having control over self and developing trust in the environment are all aspects which strengthen a young person's autonomous nature (Case-Smith, 2005) and encompass the indicators mentioned here; reciprocal respect within relationships, coping strategies, feeling valued and having a positive sense of self.

The ‘Mapping terrains’ report (Llewellyn & Leonard, 2010) identified indicators related to family within the theme of ‘identity’ and ‘parents and family’. However, there is no specific mention of the importance of sibling relationships. This study has highlighted the important role siblings play in child/youth wellbeing and should therefore be given emphasis within the indicator set. As the report mentions, and as has been highlighted by many others, ‘*young people may pick up on areas of importance or consideration that adults may overlook or misunderstand due to differences in social and cultural contexts of children and adults* (pg 9)’ (Hannafin & Brooks, 2009; Llewellyn & Leonard, 2010; NSW Commission for Children and Young People., 2005). The discussions within these groups have drawn attention to gaps within the indicator sets from the perspective of the children and young people themselves.

Interpreting scribe notes throughout the analysis of these data presents a study limitation due to potential bias of the scribe (Onwuegbuzie, 2003). Another limitation was the challenge experienced by the authors in differentiating specific quotes into different themes. For example, some quotes seem to fit into multiple themes, depending on interpretation. The quote *“sometimes kids might be playing sports and I just go talk to the adults…they usually talk about restaurants and stuff…I’ve been to lots of restaurants as well so I can have an opinion about them.”* This quote was interpreted in relation to the participant feelings of being a part of a relationship or friendship. The participant may have had a desire to be involved in the game and therefore building relationships with the other children, yet instead he had to go and spend time with ‘*the adults*.’ This quote could be argued to fit within the *‘having things to do’* theme, however, through reflection and member checking, it was agreed to be more strongly aligned with the theme regarding friendships and relationships.

Involving both children with intellectual and/or physical disabilities in this study presents a broader picture of the meaning of wellbeing. Future research could replicate this study with only children with intellectual disability or physical disabilities to gain a more insightful understanding of challenges faced by these young people and how they may conceptualize wellbeing differently. This research involved a relatively small purposive sample of children and young people with intellectual and physical disabilities. Findings from this study should be interpreted in the context of these limitations.

Further research involving the views of children and youth with disabilities on developing indicators of wellbeing is required as this research was a small scale study investigating what indicators are important for children and youth with disabilities. This research gives an indication of areas which are important to consider when examining the wellbeing of children and young people with disabilities and what gaps there may be in indicator sets for typically developing children and young people and in the one instance of an indicator set developed specifically for children and youth with disabilities from the relevant UN Conventions. The importance of involving the children and young people in researching their own lives has been highlighted through this study and acknowledges the valuable contribution these young people can offer, regardless of impairment or disability. Further consultation is required to develop the best ways of translating the perspectives of these children and young people with disabilities into measureable indicators that can be reliably used to assess, overtime, progress being made toward ensuring the ongoing wellbeing of this group of young Australians.

Table 4: Indicators, frameworks and the conventions

| Key themes in the CRC & CRPD | Themes identified by youth with disabilities in this study | Indicators | Other Frameworks | | | |
|---|---|---|---|---|---|---|
| | | | UNICEF[a] | OECED[b] | AIHW[c] | ARACY[d] |
| | | Children are respected as individuals | | | | ✓ |
| | | Children are registered and given a name | | | | |
| | | Children are afforded citizenship and nationality | | | | |
| | | Children's links to family, parents and kinship networks are maintained | ✓ | | ✓ | ✓ |
| | | Children establish friendship and kinship networks that support their identity | ✓ | | | ✓ |
| Association | ✓ | Children establish, maintain and associate with friendship networks | ✓ | | | ✓ |
| | | Children are exposed to other children in a way that is conducive to friendship | ✓ | ✓ | | ✓ |
| Protection | ✓ | The best interests of the child are of paramount concern in the development of social norms and measures. | | ✓ | | |
| | | Measures exist to protect children in times of crisis | | | ✓ | ✓ |
| | | Children are not subjected to torture, inhuman or degrading punishment or non-consensual experimentation. | | | ✓ | |
| | | Children are protected in law from cruelty | ✓ | ✓ | ✓ | ✓ |
| | | Children are protected from exploitation, violence and abuse | | ✓ | ✓ | |
| | | Children are protected from unsafe environments, including at work | | | | |
| Justice | | Children are given recognition before the law, including adequate representation and voice in legal matters | | | | |

| Key themes in the CRC & CRPD | Themes identified by youth with disabilities in this study | Indicators | Other Frameworks<br>UNICEF[a] | <br>OECED[b] | <br>AIHW[c] | <br>ARACY[d] |
|---|---|---|---|---|---|---|
| Care | ✓ | Children have access to trained professionals where appropriate in the administration of their care. |  | ✓ |  | ✓ |
| Parents and Family | ✓ | Children retain their fertility and are not subjected to arbitrary medical interventions with regard to family or the ability to found a family | ✓ |  | ✓ | ✓ |
|  |  | Children have and know their family |  |  |  |  |
|  |  | Children shall not be separated from their families against their will |  |  | ✓ |  |
|  |  | Children, where necessary, have access to appropriate alternative family situations. |  |  |  |  |
| Right to Life | ✓ | Children are protected in a way that enables their right to life | ✓ | ✓ | ✓ | ✓ |
| Expression | ✓ | Children are able to express their views on all matters effecting them |  |  |  | ✓ |
|  |  | Children are taught to express themselves, and such expression is facilitated effectively |  |  |  | ✓ |
| Participation | ✓ | Children are included in the society and social processes |  |  |  | ✓ |
|  |  | Children's participation in the home and society is supported by adequate access and environmental concerns. |  |  |  |  |
|  |  | Children's mobility needs are considered to enable participation in the home and society. | ✓ |  | ✓ | ✓ |
|  |  | Children have access to cultural materials, recreation, leisure and sport |  |  |  |  |

| Key themes in the CRC & CRPD | Themes identified by youth with disabilities in this study | Indicators | Other Frameworks | | | |
|---|---|---|---|---|---|---|
| | | | UNICEF[a] | OECED[b] | AIHW[c] | ARACY[d] |
| Privacy | ✓ | Children are entitled to privacy and protected from unlawful privacy infringement | | | | |
| Information | | Children have access to meaningful information | | ✓ | | ✓ |
| Representation | | Children are represented in media forms and are visible through such representation | | | | |
| Dignity | ✓ | No action is committed against children to deny them of inherent human dignity | ✓ | ✓ | ✓ | ✓ |
| Access | ✓ | Children have access to items in their environment, regardless of perceived or present disability or impairment | | | | |
| | | Children's mobility needs are supported | ✓ | ✓ | ✓ | ✓ |
| | | Children have access to resources of interest or meaning to them and which assists in their development | ✓ | ✓ | ✓ | ✓ |
| | | Children are able to access appropriate health support | ✓ | | | |
| | | Measures are taken to ensure that children have access to leisure, sport, recreation and cultural events, artefacts and spaces. | | | | |
| Health | ✓ | Children are provided with adequate and accessible health care and services | ✓ | ✓ | ✓ | ✓ |
| | | Children are provided with adequate and accessible rehabilitation care and services | | | ✓ | |
| Security | ✓ | Children are free from restraint or unlawful imprisonment | | | | |
| | | Children are protected from attacks on their person or environment | | | ✓ | ✓ |
| Standard of Living | | Children have access to adequate food, clothing and housing | ✓ | ✓ | ✓ | ✓ |

| Key themes in the CRC & CRPD | Themes identified by youth with disabilities in this study | Indicators | Other Frameworks | | | |
|---|---|---|---|---|---|---|
| | | | UNICEF[a] | OECED[b] | AIHW[c] | ARACY[d] |
| Education | ✓ | Children are educated to as high a level as possible | ✓ | ✓ | ✓ | ✓ |
| | | Children's education is meaningful to their full participation in society | | ✓ | | ✓ |
| | | Children's education is able to improve their access to society | ✓ | ✓ | | ✓ |
| Development | ✓ | Children are encouraged to develop emotionally, physically and mentally | ✓ | ✓ | ✓ | ✓ |
| | | Children's developmental needs are met by the society | | ✓ | ✓ | ✓ |
| Respect | ✓ | Children are treated with respect and dignity, and feel respected | ✓ | ✓ | ✓ | ✓ |
| Equality | ✓ | All children are able to access all aspects of society and family on an equal basis with others | ✓ | ✓ | | |
| | | Children are protected from discrimination in all its forms | | | | |
| Visibility | | All children, without discrimination, are visible in society, through both physical and media representation | | | | |
| Environment | | Children have a safe and supportive environment that enables their full participation in society | ✓ | ✓ | ✓ | |
| Freedom | ✓ | Children are free from restraint or unlawful imprisonment | | | | |
| Independence | ✓ | Children are, where appropriate, able to act independently from adults or carers. | | | | |

[a] UNICEF Innocenti Research Centre Working Paper, *Comparing Child Wellbeing in OECD Countries: Concepts and Methods*, IWP-2006-03, December2006

[b] OECD, *Doing Better for Children*, 2009

[c] Australian Institute of Health and Welfare, *A Picture of Australia's Children 2009*, PHE 112

[d] ARACY, *The Wellbeing of Young Australians: Technical Report*, 2008

*Note.* CRC, Committee on the Rights of the Child, CRPD, Committee on the Rights of Persons with Disabilities

## Preface to chapter four

The previous chapter highlighted the importance children and young people with disabilities place on participation as contributing to their overall wellbeing. Additionally, the previous two chapters concluded on the usefulness of the ICF in research with young people with disabilities.

This thesis is framed within the ICF and each subsequent chapter is primarily aligned with one component of the ICF in relation to the component of participation. Chapter four is titled 'Functioning in activities of daily living and participation.' This chapter is strongly associated with the activities component of the ICF which describes the execution of a task or action by an individual (World Health Organization, 2001). Chapters described within the activities component of the ICF include communication, self-care and community, social and civic life. These elements and others are assessed within the measure of functioning in activities of daily living which is employed in the following chapter of this thesis. This chapter explores the relationship between elements of the activities component and the participation component of the ICF for young adults with Down syndrome who are transitioning from school to adulthood.

The following manuscript was published in *Child: Care, Health and Development* in 2013. The full, published manuscript is provided as Appendix H.

The PhD Candidate, Kitty-Rose Foley accounted for 85% of the intellectual property associated with the final manuscript. Collectively, the remaining authors contributed 15 per cent.

# Chapter 4: Functioning in activities of daily living and participation

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## FUNCTIONING AND POST-SCHOOL TRANSITION OUTCOMES FOR YOUNG PEOPLE WITH DOWN SYNDROME

### 4.1 Abstract

Aim: To investigate the relationship between functioning and post-school day occupation for young adults with Down syndrome.

Methods: Families of young people with Down syndrome (n=269) aged 15-30 years in 2009 were recruited from the population-based Down syndrome ‘Needs Opinion Wishes’ database in Western Australia. Questionnaires were mailed to participating families and involved two parts, young person characteristics and family functioning, 203 were returned (75%). Of those families who returned questionnaires, 164 (80.8%) of their young adults had left school. Participation in post-school day occupations was the main outcome and included; open employment, training, sheltered employment or alternatives to employment (ATE).

Results: Young adults were reported as participating in open employment (n=42), training (n=17), sheltered employment (n=64) or ATE (n=41) post-school. Those who reported better functioning in self-care, community and communication skills were more likely to be in open employment and/or attending Technical and Further Education (TAFE) compared to those attending sheltered employment and/or ATE after adjusting for age, gender and rural/metropolitan regions. Current health as measured by visits to a general practitioner (GP) and hospitalisations revealed a weak relationship with post-school day occupations, with increasing likelihood of participating in open employment or training with increasing hospitalisations and GP visits.

Conclusions: Our analysis shows that functioning in activities of daily living was related to post-school day occupation. Current health status and behaviour were found to have a weak relationship with post-school day occupation adjusting for functioning in the final model.

## 4.2 Introduction

Transitioning from school to post-school activities can be a stressful and worrying period, when young adults seek to develop their own identity and make decisions about their future (Bryant, Young, Cesario, & Binder, 2010). For young people with intellectual disabilities, the challenges are intensified with additional barriers and complicated policies and services to navigate (Forte, Jahoda, & Dagnan, 2011; Zigler, Bennett-Gates, Hodapp, & Henrich, 2002). Young adults with Down syndrome, the most common genetic cause of intellectual disability, have a high prevalence of health conditions including cardiac, gastrointestinal, respiratory conditions, ear and eye disorders (Thomas et al., 2011). These health conditions can often influence both a young person's ability to function in activities of daily living (ADL) and quality of life (Halder et al., 2004; Hamann et al., 2007; Meijboom, Szatmari, & Deckers, 1995). For young people with Down syndrome transitioning from school, the extent to which functioning in activities of daily living (ADL) and participation in post-school day occupations is influenced by these health conditions is largely unknown.

The International classification of functioning, disability and health (ICF) is a framework used to classify health conditions, health related states and health outcomes and has been used to guide research for people with disabilities (World Health Organization, 2001). The value of the ICF in framing and guiding research in the area of intellectual disability is emerging in the literature (Jelsma, 2009). The change of perspectives from the traditional biomedical model of disease to a more holistic biopsychosocial model calls for consideration of a number of contextual factors which can influence people's lives. The ICF provides such a framework and also helps to inform practical changes including service definition and eligibility

(Kraus de Camargo, 2011). For the purpose of this study, participation was defined as ‘involvement in life situations’ (World Health Organization, 2001). While participation is discussed across a number of life areas, the main focus for this paper is participation in post-school day occupations. According to the World Federation of Occupational Therapists (WFOT) occupation is defined as ‘the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life’ (WFOT, 2011, Definition of Occupational Therapy, para. 2). For this thesis, occupation refers to one of four post-school day occupations which were engaged in by young people with Down syndrome. These were; open employment, training, sheltered employment or day recreation programs and will be further described in the methods section.

A study of parents of young adults with intellectual disability living in the UK identified being well-connected with other parents/professionals, being proactive within the process, having sufficient information and good forward planning as central in achieving successful transition outcomes for their son/daughter (Heslop & Abbott, 2007). An older Scottish study presented a disappointing picture post-school with young adults with Down syndrome participating in a narrow range of leisure activities with minimal placement in employment and continuing dependency on parents (Thomson et al., 1995). In Australia no clear outline exists of what constitutes good practice in relation to employment services post-school and no data is available on the long term outcomes of people working in integrated settings (Parmenter, 1999). Research in the United States has begun to investigate the role of self-determination in successful transition into adulthood for young people with intellectual disabilities (Wehmeyer & Garner, 2003; Wehmeyer & Palmer, 2003). However the extent to which level of functioning in ADLs impacts post-school outcomes remains to be investigated among young people with Down syndrome. We hypothesized that level of function in ADLs would be related to post-school outcomes with those with better function in ADLs being more likely to be participating in open employment. The factors identified in the literature may then impact on this relationship to varying extents.

Rigorous studies with large sample sizes and population-based data are sparse in the area of transition for young people with an intellectual disability (Foley, Dyke, Girdler, Bourke, & Leonard, 2012). Little is known about the specific factors which are positively or adversely related to post-school outcomes. This research was an exploratory study which investigated the relationship between functioning in ADLs and post-school day occupations for young adults with Down syndrome. Additionally, we aimed to identify those factors which may influence this relationship including the individual's physical and mental health, the type of school attended, the mother's emotional state and the level of involvement of both the young person and their parents in transition planning.

## 4.3 Methods

This study is part of a nation-wide study of young adults with intellectual disability transitioning from school to post-school. In Western Australia (WA) young people with Down syndrome were identified through the population-based Down Syndrome "Needs Opinions Wishes" study conducted in 2004 (Bourke et al., 2009). In 2009 questionnaires were distributed to those families whose children were aged between 15 and 30 years. These parent-report questionnaires consisted of two parts: part one collected information about the individual with Down syndrome including information on health, functioning and service needs, and specific transition related issues, and part two collected information about the health and wellbeing of their family. This included wellbeing of the family as a whole and the individual wellbeing of the parent who responded to the questionnaire. The research protocol was approved by the Human Research Ethics Committee of Edith Cowan University and the Princess Margaret Hospital for Children Ethics Committee.

A cross-sectional exploratory study design was chosen for this study. While cross-sectional studies do not provide an explanation for findings or a direction of causality, they do provide specific insights into the relationship between two variables (Mann, 2003). As little is known about the relationship between post-school day occupations and level of young person's functioning in ADLs, it is appropriate to initially implement an exploratory cross-sectional study.

### 4.3.1 Independent variables

As outlined in Figure 2, elements of each domain of the ICF were measured using a range of valid and reliable outcome measures, and questions with categorical responses. Descriptions of measures included are shown in Table 5.

### 4.3.1 Outcome

The participation domain of the ICF is described as 'involvement in a life situation.' Participation in day occupations was the main outcome and was categorised into either open employment, training, sheltered employment or alternatives to employment (ATE). Open employment refers to integrated employment by businesses in the community. Within open employment, some young adults may receive additional support (Paul Wehman & Revell, 1997). Training includes those attending a Technical and Further Education (TAFE) course or a post-secondary education program. Sheltered employment settings are segregated work settings for individuals with a disability. In WA, ATE programs are provided for those young adults who are not in either employment or training to support outcomes relating to social participation, increased independence, lifelong learning and enhanced support networks (Disability Services Commission, 2009). A number of the young adults were reported as attending more than one of the above day activities. When this occurred, they were classified into the activity where they spent the most time or the activity which required the highest amount of skill, as defined in consultation with a community reference group of parents of young adults with Down syndrome (see Table 6).

Figure 2: Instruments used to measure components of the ICF

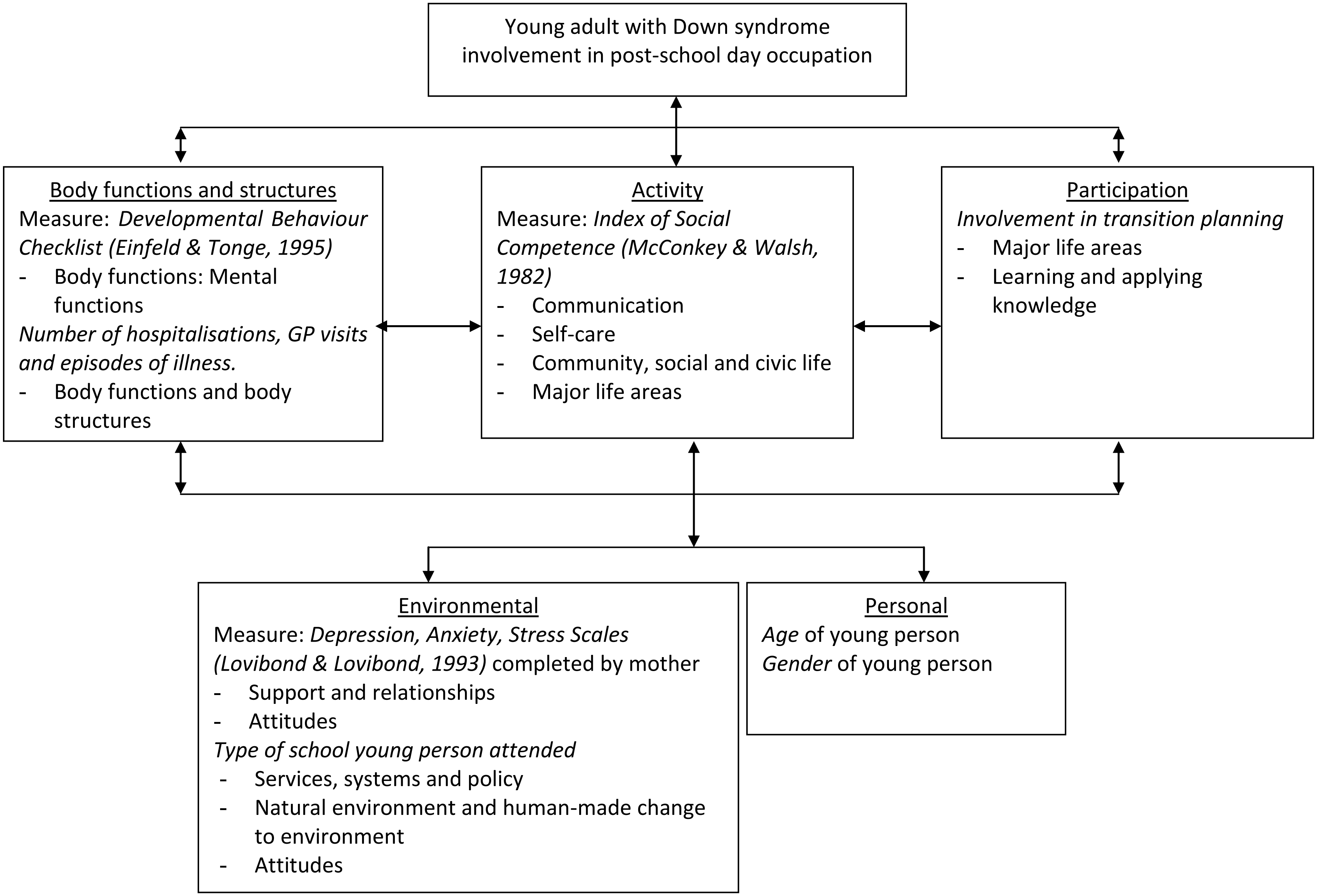

Table 5: Description of measures and variables

| ICF Domain | Construct measured | Measure | Direction of scores | Range |
|---|---|---|---|---|
| Activity | Functioning in ADLs | Index of Social Competence (McConkey, & Walsh, 1982) | Higher score=better function | Sub-domains<br>Self-care skills: 0-26<br>Communication skills: 0-11<br>Community skills: 0-19 |
| Body functions and structures | Health state | Number of hospitalizations<br>Number of GP visits<br>Number of episodes of illness | Count | Count over the previous 12 months |
| | Behaviour | Developmental Behaviour Checklist (Einfeld, & Tonge, 1995) | Higher score=more behavioural problems | 0-192 |
| Environmental factors | Mothers emotional state | Depression, Anxiety, Stress Scales (Lovibond, & Lovibond, 1993) | Higher score=more emotional disturbances | 0-63 |
| | Type of school attended | Categorical | NA | Education support school/centre<br>Education support in government school<br>Education support in a private school<br>Mainstream |
| | Living region | Categorical | NA | Metropolitan<br>Rural |
| Participation | Involvement in day occupations | Categorical | NA | Open employment<br>Training<br>Sheltered employment<br>Day recreation programs |
| | Involvement in transition planning | Categorical | NA | Not at all, a little, moderately, quite a bit or extremely |

*Note.* All measures were parent report

*Note.* NA, not applicable, ADL, activities of daily living

### 4.3.2 Data analysis

Analysis of variance and chi-square tests were used to describe univariate relationships between the factors under investigation and the outcome, involvement in day occupations. Logistic regressions with binary outcomes were used in the final models allowing adjustment for confounders identified in the univariate analyses. These included: young person's age and sex, living region, number of siblings, family income and parent's age and occupation. Unadjusted and adjusted models were reported separately. STATA 11 was used for these analyses (Statacorp, 2003).

Table 6: Description of combinations of day occupations within each group

| Post-school Day Occupation | n (%) |
|---|---|
| Open Group | 42 (100) |
| Open only | 20 (47.6) |
| Open, TAFE and ATE | 12 (28.6) |
| Open and ATE | 4 (9.5) |
| Other combination | 6 (14.3) |
| Training group | 17 (100) |
| TAFE, sheltered and ATE | 8 (47.1) |
| TAFE and ATE | 9 (52.9) |
| Sheltered Group | 64 (100) |
| Sheltered only | 49 (76.6) |
| Sheltered and ATE | 15 (23.4) |
| ATE Group | 41 (100) |
| ATE Only | 41 (100) |
| Total | 164 |

## 4.4 Results

Of the 269 questionnaires administered, 203 (75%) were returned. This study was restricted to the 164 young people with returned questionnaires who had left school. Their mean age was 22.9 years (range 15 to 29 years) and just over half

(54.9%) were male. Almost all (90.2%) lived in the family home with the majority (78.0%) living in the metropolitan area. Nearly two thirds (60.6%) were reported as having attended an education support unit in a mainstream school with the remainder attending an education support school/centre (30.3%) or attending a mainstream school (9.0%). Their mothers ranged in age from 37 to 80 years and fathers from 39 to 80 years. Compared to 55.7% of fathers, only one third of mothers, lower than the 45% reported for the Australian female population (Australian Bureau of Statistics, 2010), worked in a job rated within the highest skill level based on the Australian and New Zealand Standard Classification of Occupations (ANZSCO). Annual family income classification was guided by the Australian Bureau of Statistics classifications (Australian Bureau of Statistics., 2010) and reported as less than $33799 by 25.2%, between $33800 and $72799 by 28.8% and $72800 and above by 46.0%.

### 4.4.1 Outcome

The most common main day occupation was participation in sheltered employment, attended by 39.0% of young people (Table 7). Fewer were working in open employment (25.6%) or only attending alternatives to employment (25.0%) with a minority (10.4%) attending training as their main day occupation.

### 4.4.2 Activity

Those attending ATE scored consistently lower in community and communication skills, measured within the subscales of the Index of Social Competence, compared with those attending other day occupations (Table 7) (McConkey & Walsh, 1982). There was no difference in reported self-care functioning scores among those in open employment (mean 22.31 SD 2.87), training (mean 22.24 SD 2.88) or sheltered employment (mean 20.20 SD 3.63). The final model showed that better levels of overall functioning in ADLs increased the likelihood that the young adult would be in open employment and/or training when compared to those in sheltered employment or ATE (OR 1.14, 95% CI 1.06, 1.22) after adjusting for age, gender, behaviour, episodes of illness and mother's emotional state (Table 8). This odds ratio refers to a unit change in functioning score.

### 4.4.3 Body functions and structures

Description of presence of impairments of body functions and structures, based on the annual number of hospitalisations, number of episodes of illness and number of GP visits are shown in Table 7. Only 18.9% of young adults with Down syndrome were reported to have had one or more hospital visits in the previous twelve months. Of the 62 young adults who were reported as attending the GP four or more times in the previous year, 21 (33.9%) were attending sheltered employment and 22 (35.5%) attending ATE. Number of episodes of illness was included in the final model (Table 8) as considered the most appropriate of the health variables to represent impairment of body functions and structures. The influence of number episodes of illness in the final model was minimal (OR 1.02, 95% CI 0.87, 1.20).

There was a weak association between number of hospitalisations and number of episodes of illness with post-school day occupation (data not shown). Adjusting for confounding variables age, gender, living region, functioning, behaviour, number of siblings and family income the relationship became stronger with those participating in open employment and training more likely to report one or more hospitalisations (OR 4.39, 95% CI 0.83, 23.15)(data not shown in table).

### 4.4.1 Environment

Mothers of those young adults attending ATE had higher Depression Anxiety Stress Scales scores (Lovibond & Lovibond, 1993) representing poorer maternal emotional state (mean 65.65 SD 20.44) than those in open employment (mean 54.13 SD 19.73)(Table 7). In the final model, the influence of maternal emotional state was attenuated (Table 8).

### 4.4.2 Transition planning

Young adult and parent involvement in decision making during the transition process was rated as ‘not at all,’ ‘a little/moderately’ or ‘quite a bit/extremely.’ Of the young adults (n=52) who were reported as being ‘quite a bit/extremely’ involved in decision making during transition, 40.4% were in open employment. Of the parents (n=109) who reported being ‘quite a bit/extremely’ involved, 29.4% of their young adults were attending open employment. In the final model (Table 8) young adults who were reported as being ‘extremely’ or ‘quite a bit’ involved in decision making during the transition process (compared to ‘not at all’) were more likely to be in open employment and/or training (OR 5.4, 95% CI 1.80, 16.19). However this effect was reduced when confounding variables were included in the model (OR 3.87, 95% CI 0.73, 20.65) (see Table 8).

## 4.5 Discussion

We found that the post-school day occupation of the young adult with Down syndrome was strongly related to their level of functioning in ADLs. Not unexpectedly young adults who were reported as functioning better within self-care, community and communication skills were more likely to be participating in open employment or training than those in sheltered employment or ATE.

Those with more socially acceptable behavior were more likely to be participating in open employment or training, but after adjusting for level of functioning in ADLs this effect was reduced. Previous research has concluded that difficult behaviour can affect learning and social opportunities for young adults with Down syndrome (Buckley et al., 2006). Those able to behave in a socially acceptable manner were reported as more likely to have friends and be more successful at work (Buckley et al., 2006). Nevertheless we cannot take the direction of this relationship for granted. It is possible that the type of post-school outcome may have an influence on behaviour and not the reverse.

Table 7: Univariate analysis of impairment, activity, person and environment factors as predictors of post-school day occupation

| | | Post-school day occupation | | | | Binary post-school day occupation variables | |
|---|---|---|---|---|---|---|---|
| | Total | Open employment (n=42) | Training (n=17) | Sheltered employment (n=64) | ATE (n=41) | Open employment and training (n=59, 36.0%) | Sheltered employment and ATE (n=105, 64.0%) |
| | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) |
| Person Factors | | | | | | | |
| Gender | | | | | | | |
| Female | 74 (45.1) | 25 (59.5) | 8 (47.1) | 22 (34.4) | 19 (46.3) | 33 (55.9)* | 41 (39.1) |
| Male | 90 (54.9) | 17 (40.5) | 9 (52.9) | 42 (65.6) | 22 (53.7) | 26 (44.1) | 64 (60.9) |
| Age-group | | | | | | | |
| 15-17 year olds | 9 (5.5) | 1 (2.4) | 2 (11.8) | 3 (4.7) | 3 (7.3) | 3 (5.1) | 6 (5.7) |
| 18-22 year olds | 66 (40.2) | 16 (38.1) | 8 (47.1) | 27 (42.2) | 15 (36.6) | 24 (40.7) | 42 (40.0) |
| 23-31 year olds | 89 (54.3) | 25 (59.5) | 7 (41.2) | 34 (53.1) | 23 (56.1) | 32 (54.2) | 57 (54.3) |
| Environmental factors | | | | | | | |
| Annual family income | | | | | | | |
| $72800 and above | 51 (46.0) | 19 (57.6) | 5 (50.0) | 19 (44.2) | 8 (32.0) | 24 (55.8) | 27 (39.7) |
| Between $33800 and $72799 | 32 (28.8) | 8 (24.2) | 4 (40.0) | 12 (27.9) | 8 (32.0) | 12 (27.9) | 20 (29.4) |
| Less than $33799 | 28 (25.2) | 6 (18.2) | 1 (10.0) | 12 (27.9) | 9 (36.0) | 7 (16.3) | 21 (30.9) |
| Place of residence | | | | | | | |
| Family home | 147 (90.2) | 38 (90.5) | 15 (88.2) | 57 (89.1) | 37 (92.5) | 53 (89.8)* | 94 (90.4) |
| Group home/hostel | 7 (4.3) | 0 | 0 | 4 (6.3) | 3 (7.5) | 0 | 7 (6.7) |
| Living alone | 5 (3.1) | 2 (4.8) | 1 (5.9) | 2 (3.1) | 0 | 3 (5.1) | 2 (1.9) |
| Living with family/friends | 4 (2.5) | 2 (4.8) | 1 (5.9) | 1 (1.6) | 0 | 3 (5.1) | 1 (0.1) |

| | Post-school day occupation | | | | | Binary post-school day occupation variables | |
|---|---|---|---|---|---|---|---|
| | Total | Open employment (n=42) | Training (n=17) | Sheltered employment (n=64) | ATE (n=41) | Open employment and training (n=59, 36.0%) | Sheltered employment and ATE (n=105, 64.0%) |
| | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) |
| Living Region | | | | | | | |
| Metropolitan WA | 124 (78.0) | 28 (70.0) | 11 (68.7) | 54 (85.7) | 31 (77.5) | 17 (30.4) | 18 (17.5) |
| Rural WA | 35 (22.0) | 12 (30.0) | 5 (31.3) | 9 (14.3) | 9 (22.5) | 39 (69.6) | 85 (82.5) |
| Type of school attended | | | | | | | |
| Mainstream | 14 (9.0)* | 6 (14.3) | 2 (12.5) | 3 (5.1) | 3 (7.9) | 8 (6.1) | 6 (6.1) |
| Education support unit in mainstream school (Government) | 55 (35.5) | 18 (42.9) | 3 (18.8) | 23 (39.0) | 11 (29.0) | 21 (36.2) | 34 (35.1) |
| Education support unit in mainstream school (Private) | 39 (25.2) | 13 (31.0) | 9 (56.3) | 11 (18.6) | 6 (15.8) | 22 (37.9) | 17 (17.5) |
| Education Support School/Centre | 47 (30.3) | 5 (11.9) | 2 (12.5) | 22 (37.3) | 18 (47.4) | 8 (12.7) | 6 (6.1) |
| Parent demographics | | | | | | | |
| Mothers age | | | | | | | |
| 37 to 45 years old | 10 (6.1) | 1 (2.4) | 0 | 7 (10.9) | 2 (4.9) | 1 (1.7) | 9 (8.6) |
| 46 to 55 years | 76 (46.3) | 21 (50.0) | 8 (47.1) | 31 (48.4) | 16 (39.0) | 29 (49.2) | 47 (44.8) |
| 56 years and older | 78 (47.6) | 20 (47.6) | 9 (53.0) | 26 (40.6) | 23 (56.1) | 29 (49.2) | 49 (46.7) |
| Fathers age | | | | | | | |
| 39 to 45 years old | 8 (5.5) | 0 | 0 | 4 (7.1) | 4 (11.8) | 0 | 8 (8.9) |
| 46 to 55 years | 58 (39.7) | 17 (41.5) | 6 (40.0) | 22 (39.3) | 13 (38.2) | 23 (41.2) | 35 (38.9) |
| 56 to 65 years | 59 (40.4) | 17 (41.5) | 9 (60.0) | 22 (39.3) | 11 (32.4) | 26 (46.4) | 33 (36.7) |
| 66 years and older | 21 (14.4) | 7 (17.1) | 0 | 8 (14.3) | 6 (17.7) | 7 (12.5) | 14 (15.6) |

| | Post-school day occupation | | | | | Binary post-school day occupation variables | |
|---|---|---|---|---|---|---|---|
| | Total | Open employment (n=42) | Training (n=17) | Sheltered employment (n=64) | ATE (n=41) | Open employment and training (n=59, 36.0%) | Sheltered employment and ATE (n=105, 64.0%) |
| | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) |
| Mother's occupation | | | | | | | |
| 1 - Managers | 32 (33.0) | 10 (38.5) | 3 (33.3) | 12 (27.3) | 7 (39.9) | 19 (30.7) | 13 (37.1) |
| 2- Professionals/technicians/ trades workers | 16 (16.5) | 6 (23.1) | 2 (22.2) | 2 (4.6) | 6 (33.3) | 8 (12.9) | 8 (22.9) |
| 3- Community/Personal Service workers | 49 (50.5) | 10 (38.5) | 4 (44.4) | 30 (68.2) | 5 (27.8) | 35 (56.5) | 14 (40.0) |
| Father's occupation | | | | | | | |
| 1 - Managers | 44 (55.7) | 18 (60.0) | 4 (66.7) | 13 (52.0) | 9 (50.0) | 22 (51.2) | 22 (61.1) |
| 2- Professionals/technicians/ trades workers | 14 (17.7) | 4 (13.3) | 1 (16.7) | 3 (12.0) | 6 (33.3) | 9 (20.9) | 5 (13.9) |
| 3- Community/Personal Service workers | 21 (26.6) | 8 (26.7) | 1 (16.7) | 9 (36.0) | 3 (16.7) | 12 (27.9) | 9 (25.0) |
| Impairment factors | | | | | | | |
| Annual GP visits | | | | | | | |
| 0-1 | 29 (19.2) | 12 (30.8) | 2 (13.3) | 11 (18.6) | 4 (10.5) | 14 (25.9) | 15 (15.5) |
| 2 | 38 (25.2) | 9 (23.1) | 2 (13.3) | 20 (33.9) | 7 (18.4) | 11 (20.4) | 27 (27.8) |
| 3 | 22 (14.6) | 5 (12.8) | 5 (33.3) | 7 (11.9) | 5 (13.2) | 10 (18.5) | 12 (12.4) |
| 4 or more | 62 (41.1) | 13 (33.3) | 6 (40.0) | 21 (35.6) | 22 (57.9) | 19 (35.2) | 43 (44.3) |
| Episodes of illness | | | | | | | |
| 0-1 | 25 (21.6) | 10 (30.3) | 4 (28.6) | 4 (10.0) | 7 (24.1) | 14 (29.8) | 11 (15.9) |
| 2-3 | 50 (43.1) | 12 (36.4) | 6 (42.9) | 19 (47.5) | 13 (44.8) | 18 (38.3) | 32 (46.4) |

| | Post-school day occupation | | | | | Binary post-school day occupation variables | |
|---|---|---|---|---|---|---|---|
| | Total | Open employment (n=42) | Training (n=17) | Sheltered employment (n=64) | ATE (n=41) | Open employment and training (n=59, 36.0%) | Sheltered employment and ATE (n=105, 64.0%) |
| | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) | Freq (%) |
| 4 or more | 41 (35.3) | 11 (33.3) | 4 (28.6) | 17 (42.5) | 9 (31.0) | 15 (31.9) | 26 (37.7) |
| Hospital visits | | | | | | | |
| None | 133 (81.1) | 33 (78.6) | 14 (82.3) | 53 (82.8) | 33 (80.5) | 47 (79.7) | 86 (81.9) |
| 1 or more | 31 (18.9) | 9 (21.4) | 3 (17.7) | 11 (17.2) | 8 (19.5) | 12 (20.3) | 19 (18.1) |
| Activity | | | | | | | |
| Using a telephone | | | | | | | |
| Successful most of the time/all of the time | 44 (27.7)* | 23 (54.8) | 5 (31.3) | 10 (16.1) | 6 (15.4) | 28 (48.3)* | 16 (15.8) |
| Most of the time, with some assistance | 26 (16.4) | 8 (19.1) | 4 (25.0) | 9 (14.5) | 5 (12.8) | 12 (20.7) | 14 (13.9) |
| Some of the time | 40 (25.2) | 8 (19.1) | 6 (37.5) | 22 (35.5) | 4 (10.3) | 14 (24.1) | 26 (25.7) |
| Not at all | 49 (30.8) | 3 (7.1) | 1 (6.3) | 21 (33.9) | 24 (30.8) | 4 (6.9) | 45 (44.6) |
| Participation | | | | | | | |
| Young person involvement in transition planning | | | | | | | |
| Not at all | 32 (21.9) | 1 (2.6) | 4 (26.7) | 11 (19.6) | 16 (44.4) | 5 (9.3)* | 27 (29.4) |
| A little/moderately | 62 (42.5) | 17 (43.6) | 6 (40.0) | 30 (53.6) | 9 (25.0) | 23 (42.6) | 39 (42.4) |
| Quite a bit/extremely | 52 (35.6) | 21 (53.9) | 5 (33.3) | 15 (26.8) | 11 (30.6) | 26 (48.2) | 26 (28.3) |
| Parent involvement in transition planning | | | | | | | |
| Not at all | 7 (4.6) | 0 | 4 (26.7) | 3 (5.2) | 0 | 4 (7.1) | 3 (3.2) |
| A little/moderately | 35 (23.2) | 9 (22.0) | 2 (13.3) | 13 (22.4) | 11 (29.7) | 11 (19.6) | 24 (25.3) |
| Quite a bit/extremely | 109 (72.2) | 32 (78.1) | 9 (60.0) | 42 (72.4) | 26 (70.3) | 41 (73.2) | 68 (71.6) |

*Note.* GP, General Practitioners, ATE, Alternatives to Employment

Table 8: Activity, participation and contextual factors in relation to post-school day occupations: binary logistic regression of univariate and adjusted models

| | | | Outcome | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | Univariate models | | | Adjusted model | | |
| Predictors | | | Day Occupation | | | Day Occupation | | |
| | | | (Open and Training vs Sheltered and ATE) | | | (Open and Training vs Sheltered and ATE) | | |
| | | | OR | 95% CI | P values | OR | 95% CI | P values |
| *Adjusted model includes all variables in one model | Functioning in ADLs (total score) | | 1.13 | 1.08, 1.19 | <0.001*** | 1.14 | 1.06, 1.22 | <0.001*** |
| | Behaviour (DBC) | | 0.98 | 0.96, 0.99 | 0.007** | 0.99 | 0.97, 1.03 | 0.867 |
| | Episodes of illness | | 0.98 | 0.87, 1.12 | 0.813 | 1.02 | 0.87, 1.20 | 0.831 |
| | Mother's emotional state (DASS total) | | 0.98 | 0.97, 0.99 | 0.045* | 0.99 | 0.97, 1.02 | 0.935 |
| | Age | | 1.03 | 0.94, 1.12 | 0.571 | 0.94 | 0.85, 1.10 | 0.582 |
| | Gender | | 0.50 | 0.26, 0.96 | 0.038* | 0.82 | 0.33, 2.01 | 0.664 |
| Participation | | | | | | | | |
| Young adult's involvement in transition planning | | | | | | | | |
| Not at all | | 32 (21.9) | | Baseline | | | Baseline | |
| A little/moderately | | 62 (42.5) | 3.18 | 1.08, 9.42 | 0.036* | 1.84 [a] | 0.38, 8.83 | 0.446 |
| Quite a bit/extremely | | 52 (35.6) | 5.40 | 1.80, 16.19 | 0.003** | 3.87 [a] | 0.73, 20.65 | 0.113 |

*Note.* ATE, Alternatives to Employment, ADLs, Activities of Daily Living, GP, General Practitioner, DBC, Developmental Behaviour Checklist, DASS, Depression Anxiety Stress Scales

*Note.* * p < 0.05. **p < 0.01. ***p < 0.001

[a] Adjusted for age, gender, living region, functioning, behaviour, number of siblings and family income

We had anticipated that poor health status would adversely impact workplace participation among young people with Down syndrome. We found only a weak relationship between number of episodes of illness and visits to general practitioners and post-school day occupations. In the univariate model more than four GP visits equated with less likelihood of being in open employment while we saw the reverse in the multivariate model. We also found that those who were reported to be attending hospital one or more times were more likely than those with no hospital admissions to be participating in open employment or training compared to participating in sheltered employment or ATE. This finding contradicted our initial hypothesis. However, investigation of reasons for hospitalisations revealed that those in open employment or training were attending hospital for more preventative and elective surgeries such as removal of wisdom teeth, removal of tonsils and circumcision. In contrast, the causal pattern for those attending sheltered employment or ATE was different and included conditions such as sleep apnea, heart conditions, 'blocked kidney' or psychiatric assessment. Count of hospital visits did not prove to be a useful measure of health state for this population. We have previously shown that health appears to improve with age among this population (Thomas et al., 2010) and improvements in medical management over the past two generations have played a role in increasing the life expectancy for people with Down syndrome (Bittles et al., 2006; Thomas et al., 2010). We could therefore speculate that improvements in medical management may also have reduced the influence on young adult participation in day occupation.

Young adults' personal involvement in transition planning has been reported as an important element when transitioning from school to post-school and a factor which helps young people achieve their desired outcomes and is associated with positive outcomes such as better quality of life (Halpern, 1999; Laragy, 2004; Wehmeyer, 1998). We found a strong relationship between young people's involvement in decision making during the transition process and their participation in open employment and/or training even after adjusting for age, gender, functioning in ADLs and behaviour. This supports previous evidence (Laragy, 2004) of the importance of young adult involvement in decision making during transition planning. Interestingly, after adjusting for family income and size this relationship reduced. This could be due to decreased availability of parental time to act as advocates for their son/daughter or decreased opportunities to access additional support due to financial constraints (Davies & Beamish, 2009). A similar pattern was found in relation to the type of school the young person attended. That is, there was a strong relationship with a young person attending an education support unit in a private school and subsequent open employment and training. However, the inclusion of family income reduced the strength of this relationship, suggesting that family income and potentially other socio-economic variables also influence post-school day occupation. This finding is consistent with research with typically developing young people which found low socio-economic communities to be disadvantaged in terms of vocational transition (Marks, 2006). Others have raised the issue that personal factors may contribute to motivation for participating in post-school education, regardless of disability status. These included preference for leisure, risk avoidance, lack of openness to new experiences and an aversion to an external locus of control (Fouarge, Schils, & de Grip, 2010; Polidano & Vu, 2011). These were not explored in the current study and warrant further investigation.

The ICF provided a useful framework for this study to examine the relationships between different components of personal and family life and post-school day occupation. The ICF allowed the exploration of the association of elements of activity limitations, such as poor functioning in self-care, communication and community skills, with elements of participation, such as type of post-school day occupation attended. The clear relationship between limitations in the activity domain associated with varying participation highlights important dynamics within the ICF framework. We found less of a relationship between health factors, which we aligned with the body functions and structures domain, and participation than we did with activity and participation. The fact that the health of many young adults with Down syndrome has considerably improved suggests a decrease in additional burden on the health system (Geelhoed, Bebbington, Bower, Deshpande, & Leonard, 2011). We have also shown that at this stage in the life of young people with Down syndrome, health issues would not appear to be one of the major barriers to participation in optimal post-school day occupation.

The interaction of contextual factors, environmental and personal factors with the other domains of the ICF revealed complex relationships. The ICF acknowledges that each one of these entities has the potential to modify one or more of the others and that it is important to collect data on these constructs independently to explore associations and possible causal links between them (World Health Organization, 2001). This is supported by the findings from the multivariate models through the influence of environmental factors such as family income and size. Environmental factors would appear to be having equivalent impact on young adult post-school day occupation as factors such as behaviour profile, which may be intrinsic to the persons themselves. Environmental factors such as availability of services, family involvement, social support and positive attitudes have been reported as critical for participation for people with intellectual disabilities (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009b). Other authors have highlighted that different elements of the environment can act as facilitators and barriers at the one time (Noreau & Boschen, 2010). This highlights the importance of conceptualising the environment as a multi-dimensional rather than a one-dimensional construct (Noreau & Boschen, 2010). Further research is needed to investigate the impact of specific environmental factors on community and workplace participation for young people with intellectual disability.

### 4.5.1 Limitations

Difficulties measuring the individual domains of the ICF have been widely reported (Hammel et al., 2008; Verdonschot et al., 2009b). We acknowledge that the measurement tools did not measure each domain in their entirety, yet they were the most appropriate measures for the population and provide accurate assessment of elements in each domain. Measuring the macro-levels of the ICF cannot be done easily, and the use of the second or third ICF classification levels may be needed to identify concepts precisely (Noreau & Boschen, 2010). Specifically, the measure for impairments of body functions and structures underscored difficulties in interpreting results. The hierarchical classification of the main outcome, participation in post-school day occupations, was also a limitation of this research. This classification was developed following consultation with a consumer reference group and industry partners to ensure the best possible interpretation according to families' experiences and current policy and legislation in WA. The fact that the data for this study was collected at one point in time, limits our ability to make assumptions about variables predicting the range of post-school outcomes. This information provides valuable insight into relationships between variables, but additional research, including longitudinal studies are needed to identify predictors. Strengths of this research include the use of a population-based database and a high response fraction.

## 4.6 Conclusion

This study highlights the relationship between functioning in ADLs and post-school day occupations. We have shown that the relationship between poor behaviour and post-school day occupations is accounted for by level of functioning in ADLs. This finding suggests changes are required in Western Australian transition processes which currently view poor behaviour irrespective of level of functioning as an indicator that a young adult should be directed towards ATE as a post-school day occupation (Disability Services Commission., 2010). Contrary to the initial hypothesis, we did not identify a strong relationship between health issues and young adult's post-school day occupation, although limitations with the surrogate measure of impairment requires careful interpretation of this finding. Finally, the use of the ICF in this study has shown the value of the framework in guiding study designs in a complex issue, transition from school for young adults with Down syndrome.

## Preface to chapter five

The previous chapter of this thesis explored the relationship between the activities component of the ICF and its relationship with participation for young adults with Down syndrome. The next chapter explores elements of a different component of the ICF, environmental factors. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives (World Health Organization, 2001). For people with intellectual disabilities, immediate and extended family play a key role in facilitating participation in employment, leisure, personal and recreational activities (Kohler & Field, 2003; Povee, Roberts, Bourke, & Leonard, 2012). According to the ICF, support from family and friends, are environmental factors. The following chapter explores the relationship between family quality of life and young persons' participation in day occupations.

This manuscript has been published in *Social Psychiatry and Psychiatric Epidemiology*.

The PhD Candidate, Kitty-Rose Foley accounted for 85% of the intellectual property associated with the final manuscript. Collectively, the remaining authors contributed 15 per cent.

# Chapter 5: Family quality of life and participation

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## RELATIONSHIP BETWEEN FAMILY QUALITY OF LIFE AND DAY OCCUPATIONS OF YOUNG PEOPLE WITH DOWN SYNDROME

### 5.1 Abstract

Purpose: To explore relationships between family quality of life, day occupations and activities of daily living (ADL) of young persons with Down syndrome.

Method: Data were collected from 150 families with a young person with Down syndrome aged 16 to 30 years participating in the Down syndrome “Needs Opinions Wishes” database. Data described the young person’s characteristics including functional abilities, behaviour and day occupations, and family characteristics including income, family and community supports and quality of life.

Results: Compared to families of young people attending open employment, families of young people participating in sheltered employment tended to report poorer family quality of life, after adjusting for personal characteristics, behaviour and income (coeff -6.78, 95%CI -14.38, 0.81). Family supports reduced this relationship (coeff -6.00, 95%CI -12.76, 0.76). Families of young people with greater functioning in ADL reported better family quality of life regardless of personal and environmental factors (coeff 0.45, 95%CI 0.05, 0.85) and inclusion of family factors such as family supports reduced this association (coeff 0.29, 95%CI -0.10, 0.67)

Conclusions: Participation of young people with Down syndrome in open employment may positively influence family quality of life. Services that facilitate functioning in ADL and assist the families in accessing suitable family supports have the potential to positively influence family quality of life.

## 5.2 Introduction

The concept of family quality of life has emerged in the literature as an extension of individual quality of life. Young people with intellectual disability often reside at home well into adulthood, highlighting the importance of describing family quality of life for this population (Parish, Pomeranz, Hemp, Rizzola, & Braddock, 2001; Turnball, Turnball, Erwin, & Soodak, 2006). However, there are considerable challenges and issues when attempting to measure family quality of life. For example, difficulties in defining the complex idea of family, issues conceptualizing family quality of life and differing opinions and perspectives on the families quality of life from different members of the family (Summers, Poston, Turnball, Marquis, Hoffman et al., 2005; Park, Hoffman, Marquis, Turnball, Poston, et al., 2003). There have also been criticisms of the nature of family quality of life research to focus on indicators of dysfunction including parental stress (e.g. Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008), poor mental health (e.g. Lach, Kohen, Garner, Brehaut, Miller, et al., 2009), and caregiver burden (e.g. Al-Krenawi, Graham, & Al Gharaibeh, 2011) (Gardiner, & Iarocci, 2012). Gardiner and Iarocci (2012) also pointed out that many family quality of life instruments only measure negative dimensions (e.g. Parenting Stress Index, Abidin, 1990). The importance of considering the ways in which families of children and young people with developmental disability may be resilient in successfully managing stressors and adjusting to life cycle transition should also be assessed and reported (Iarocci, Virju-Babul, & Reebye, 2006; Gardiner, & Iarocci, 2012).

The importance of attempting to measure the complex concept of family quality of life is highlighted by the fact many disability services are concerned with family quality of life through '*family centered*' models of service delivery (Samuel, Rillotta, & Brown, 2012). A better understanding of the types of factors that could influence quality of life in families of young persons with a disability is required (Davis & Gavidia-Payne, 2009).

Down syndrome is the most common cause of intellectual disability and is a chromosomal birth disorder which affects approximately 1 in 650 to 1000 live births in Australia (Bittles et al., 2006; Fitzgerald, Leonard, Pikora, Bourke, & Hammond, 2013). Young people with Down syndrome have varying abilities in functioning in activities of daily living (ADL), cognitive functioning, behaviour and social skills (Bourke et al., 2009; Foley et al., 2013; Roizen & Patterson, 2003). Often young people with Down syndrome live with their families well into adulthood and remain dependent on them for support and assistance to participate in activities. Families and carers of people with Down syndrome face increasing emotional and financial burdens as the young people transition out of school and into adulthood, potentially impacting on family quality of life (Bittles & Glasson, 2004; Jokinen & Brown, 2010).

Parents of young people with severe intellectual disability have described the transition from school to post-school day occupations as their ‘second shock’, after the initial shock at diagnosis (Hanley-Maxwell et al., 1995). An Australian questionnaire study administered to families with a young adult with intellectual disability found that lack of post-school options had negative implications for the whole family in terms of satisfaction and family adjustment (Davies & Beamish, 2009). There was substantial impact on families’ routines and responsibilities and the young people with intellectual disability were at risk of poorer quality of life (Davies & Beamish, 2009). Other studies have found that participation in the workforce enables the development of social relationships at work and a better quality of life (Hughes, 2001; Jahoda et al., 2008) with those in open employment more likely to report better job satisfaction and higher quality of life than those in sheltered employment, irrespective of the nature of the work or level of functional ability (Jahoda et al., 2008; Kober & Eggleton, 2005). However, the relationships between types of employment engaged in by the young person and family quality of life have not yet been investigated.

Since the introduction of the national Disability Services Act in 1986, the Australian government has put considerable effort into increasing the number of people with a disability in the workforce. Although more people with a significant disability overall are in open employment, there has been little increase in the proportion of those with an intellectual disability accessing open employment (Tuckerman et al., 2012). For example, there was a 3% rise in the number of people with intellectual disability utilising an Employment Support Service to gain open employment compared to a 186% increase for people with any disability in the period 1998 to 2010 (Tuckerman et al., 2012). At the same time, there was a 20% increase in the number of people with an intellectual disability attending sheltered employment. Of the 15,443 people attending sheltered employment in Australia in 2008, 70% of those have an intellectual disability. There was also an 18% increase from 2003 to 2010 in the number of people with intellectual disability attending state funded day recreation programs (Tuckerman et al., 2012). The implications of these patterns of occupation on families of young people with intellectual disability are unknown, in part due to the paucity of research on the relationship between type of day occupation and family quality of life.

The importance of family support during the transition period from school to adult life is well documented and this likely influences family quality of life (Dyke, Bourke, Llewellyn, & Leonard, 2013; Foley, Dyke, et al., 2012; Knox et al., 2000; Spring et al., 2002; Timmons et al., 2004; Van Cleve et al., 2006; Winn & Hay, 2009). Challenges assessing family quality of life have restricted the amount of research in this area. Recent developments of specific family quality of life measures for families of young people with intellectual and developmental disabilities make this possible (Hoffman, Marquis, Poston, Summers, & Turnball, 2006). The aims of this study were to describe the quality of life of families with a young adult with Down syndrome who had transitioned from school to post-school and influences of the young person's post-school day occupation and personal and environmental factors on family quality of life.

## 5.3 Methods

Similarly to chapter 4 of this thesis, a cross-sectional study design was chosen as the most appropriate research design (Foley et al., 2013). As the 2009 questionnaires had largely being collected at the time of onset of this PhD, these data were available for data cleaning and analysis. A clear indication of domains to focus further exploration, were prescribed as a result of the qualitative study of this thesis (chapter 3). One of the main themes which emerged from the qualitative study was regarding family functioning and participation. The justification for the design and scope of this study was resultant of the qualitative study, a thorough review of the literature and consultation with the consumer reference group and industry partners.

### 5.3.1 Participants

Recruitment for this study was from a population-based database of young people with Down syndrome in Western Australia. The database was originally formed by identification of cases from the IDEA database (Intellectual Disability Exploring Answers), which uses multiple sources to ascertain intellectual disability in Western Australia (Petterson et al., 2005). Ethics approval for this study was sort through both the Human Research Ethics Committee of Edith Cowan University and the Princess Margaret Hospital for Children Ethics Committee. Parent report questionnaires were sent to families of the young people who were post-school in 2009, identified from the 363 families who had responded to a questionnaire in 2004 (Bourke et al., 2009). A parent support group was consulted during questionnaire production to ensure that it was applicable and appropriate. In 2009, 203 (88.6%) of 229 families of the young adults aged 16 to 30 years of age returned a questionnaire, of which 150 were post-school and included in this study.

### 5.3.2 Measures

The questionnaire collected information about the young person's characteristics and family functioning. Family quality of life was measured with the Beach Centre Family Quality of Life scale (BCFQOL) (Hoffman et al., 2006), a 25-item self-report scale which measures family quality of life with level of satisfaction being the primary response format (Wang et al., 2004; Zuna, Selig, Summers, & Turnball, 2009). The subscale scores of the BCFQOL were calculated as averages of the items rated within each subscale. This procedure accounted for the missing data and ensured minimal exclusion of respondent answers (Beach Center on Disability., 2003). However, if the questionnaire was missing more than 3 responses to the 25 items, the participant was excluded from the analysis. Convergent validity of this scale has been examined in relation to the Family Resources Scale (Dunst & Leet, 1987), and the Family Adaptability, Participation, Growth, Affection and Resolution questionnaire (APGAR) (Smilkstein, Ashworth, & Montano, 1982). The BCFQOL has been validated in populations of families of typically developing kindergarten children (Zuna et al., 2009) and of families of children with disabilities (Wang et al., 2004).

For the young person with Down syndrome, functioning in activities of daily living (ADL) was assessed using the subscales of the Index of Social Competence (Foley et al., 2013; McConkey & Walsh, 1982), validated in a cohort of adults with intellectual disabilities (Dodd et al., 2008; Guerin et al., 2009; McConkey & Mezza, 2001) and with caregivers of adults with intellectual disabilities (McHale, McEvoy, & Tierney, 2009). The Developmental Behaviour Checklist Adult version (DBC-A)(Einfeld & Tonge, 1995) is a 107-item checklist completed by families or carers and was used to assess behavioural and emotional problems (Mohr, Tonge, Einfeld, & Taffe, 2011). Convergent validity has been demonstrated with two professional administered measures of behaviour disturbances in children with intellectual disability (Einfeld & Tonge, 1995). High inter-rater reliability between teachers and parents, high test-retest reliability and internal consistency and sensitivity to change has been reported (Einfeld & Tonge, 1995).

Data describing the young person's health included counts of episodes of illness, visits to a general practitioner, and number of hospitalisations in the previous twelve months. Personal factors included the young person's age and gender. Environmental factors included the type of school the young person attended, place of residence, living region (rural or metropolitan), parental occupation, age and total family income. The Family Needs Scale was used to measure the informal assistance needs of families including needs for resources and support (Dunst, Trivette, & Jenkins, 1988). The Family Support Scale was used to assess family supports including immediate family, relatives, friends and others on the family's social network (Dunst, Jenkins, & Trivette, 1984).

Post-school day occupations were categorised into the following: 1) Open employment, describing work in a mainstream setting with support; 2) Training, referring to ongoing education; 3) Sheltered employment describing employment within segregated work settings for people with a disability (in Australia, these are termed Australian Disability Enterprises, however the term sheltered employment will be employed throughout this paper.); and 4) day recreation programs which are termed 'Alternatives To Employment (ATE)' in Australia. These refer to programs specifically developed for young people who are unable to participate in employment or further training. Young adults were likely to be participating in a combination of day occupations. To categorise day occupation alternatives into mutually exclusive groups, experts within the team and the Down syndrome parent group were consulted extensively. It was agreed that the young adults would be classified into the day occupation which was assumed to require the greatest skill level. Within the questionnaire parents were also asked to respond to an open ended question asking the reason why the young person was not participating in their desired day occupation.

### 5.3.3 Statistical analysis

Descriptive statistics of univariate relationships between personal (gender, age, health state etc) and environmental (family income, type of school attended, place of residence etc) characteristics were investigated through chi-square and oneway Analysis of Variance tests. These initial analyses informed the development of steps for linear regression analyses to assess influences on family quality of life.

The steps for the hierarchical regression analyses were strategically developed as a result of the initial univariate analyses and from input from experts within the research team and the Down syndrome parent group. The regression analyses involved three steps, where different variables are added at each step. The variables added at each step were agreed upon with the research team and the Down syndrome parent group prior to analyses to ensure we could interpret the regression analyses appropriately and gain the maximum amount of information and insight from these data. At step one, age, gender, parental work status and family income were adjusted to provide a baseline description for each predictor variable of interest and family quality of life. These variables reflect socio-economic status and personal factors which are relatively stable. At step two, young person characteristics in activities of daily living and behaviour were included, factors which could be targeted in interventions and potentially improved. At step three, environmental characteristics including family supports and informal assistance needs were included in the model. These factors are known contributors to family quality of life and were added to the model in the last step in order to initially investigate the effect of other variables and then subsequently examine the entire analysis.

Families' descriptions of why their son/daughter was not participating in their desired day occupations were analysed using content analysis. Recurring words, phrases or ideas were identified by coding all data and codes were then organised into themes. Frequencies of codes within each theme were described.

## 5.4 Results

One hundred and fifty families of young people aged 16 to 29 years (mean 22.9 SD 3.6) returned questionnaires providing data about family quality of life and post-school day occupations. The majority of young people (n=134, 89.3%) were living in the family home with more living in the metropolitan area (n=116, 77.3%) than rurally (n=34, 22.7%). Young people were participating in open employment (n=38, 25.3%), sheltered employment (n=59, 39.1%), training (n=16, 10.6%) and day recreation programs (n=37, 24.7%). Some young people were participating in a combination of day occupations (see Table 9). The number of hours per week of participation in open employment ranged from 2-35 (median 9). For those participating in sheltered employment, hours ranged from 6-40 (median 20). Families of those young people attending open employment reported the highest family quality of life scores (mean 107.15 SD 13.63), followed by families of those attending training (mean 102.91 SD 18.85), sheltered employment (mean 94.91 SD 16.01) and day recreation programs (mean 93.24 SD 22.25).

Univariate relationships between family quality of life and characteristics of the young person are described in Table 10 and between family quality of life and family characteristics in Table 11. Families of young people with more behaviour problems reported lower family quality of life (mean 92.91 SD 17.59) than families of those with less behaviour problems (mean 103.16 SD 17.81). Those whose young people had better functional abilities reported better family quality of life than families of those who were less able. Families who received more support reported better family quality of life (mean 104.36 SD 15.71) than those receiving less support

Table 9: Distribution of post-school day occupations (n=150)

| Post-school Day Occupation | n (%) | Median hours per week (range) |
|---|---|---|
| Open employment (n=38) | | |
| Open only | 20 (52.6) | 9 (2-35) |
| Open, TAFE and day recreation programs | 10 (26.3) | |
| Open and day recreation programs | 4 (10.5) | |
| Open, sheltered and day recreation programs | 2 (5.3) | |
| Open and sheltered | 2 (5.3) | |
| Training group total (n=16) | | |
| TAFE, sheltered and day recreation programs | 8 (50) | - |
| TAFE and day recreation programs | 8 (50) | |
| Sheltered employment (n=59) | | |
| Sheltered only | 45 (76.3) | 20 (6- 40) |
| Sheltered and day recreation programs | 14 (23.7) | |
| Day recreation programs (n=37) | | - |
| Day recreation programs only [a] | 37 (100) | |

*Note.* TAFE, Technical and Further Education

*Note.* Hours unknown for Training and day recreation programs groups

[a] There were 46 additional young adults who participated in day recreation programs to some extent

Table 10: Univariate relationships between Beach Centre Family Quality of Life Score (BCFQOL) and young person factors (n=150)

| Young person factors | | Number | BCFQOL mean (SD) | P-value |
|---|---|---|---|---|
| Gender | Female | 69 | 100.06 (19.38) | |
| | Male | 81 | 97.08 (17.49) | 0.324 |
| Age (years) | 15-17 | 7 | 82.66 (18.64) | |
| | 18-22 | 62 | 99.59 (16.94) | |
| | 23-31 | 81 | 98.94 (19.01) | 0.064 |
| Living Region | Metropolitan WA | 116 | 97.78 (18.54) | |
| | Rural WA | 34 | 100/75 (17.90) | 0.408 |
| Type of residence | Family home | 134 | 98.71 (18.19) | |
| | Group home/hostel | 7 | 85.35 (23.44) | |
| | Living alone | 4 | 108.88 (12.58) | |
| | Living with family/friends | 4 | 102.25 (17.08) | 0.171 |
| Day occupation | Open employment | 38 | 107.15 (13.63) | |
| | Training | 16 | 102.91 (18.85) | |
| | Sheltered employment | 59 | 94.91 (16.01) | |
| | Day recreation programs | 37 | 93.23 (22.56) | 0.001 |
| GP visits [a] | 0-1 | 25 | 101.48 (14.16) | |
| | 2-3 | 58 | 101.52 (14.57) | |
| | 4 or more | 55 | 93.10 (21.97) | 0.028 |
| | Missing | 12 | NA | |

| Young person factors | | Number | BCFQOL mean (SD) | P-value |
|---|---|---|---|---|
| Episodes of illness [a] | 0-1 | 23 | 102.35 (16.44) | |
| | 2-3 | 45 | 99.86 (16.82) | |
| | 4 or more | 39 | 96.35 (21.63) | 0.448 |
| | Missing | 43 | NA | |
| Hospital visits [a] | None | 122 | 97.66 (10.06) | |
| | 1 or more | 28 | 101.88 (14.87) | 0.275 |
| Behaviour (Developmental Behaviour Checklist) | Less behaviour problems | 81 | 103.16 (17.81) | |
| | More behaviour problems | 69 | 92.91 (17.59) | <0.001 |
| | Below psychiatric cutoff | 127 | 99.96 (18.26) | |
| | Above psychiatric problems cut-off (>=51) | 23 | 90.08 (17.08) | 0.017 |
| Functioning in ADL (Index of Social Competence) | Better self-care skills [b] | 85 | 102.18 (17.83) | |
| | Poorer self-care skills [b] | 65 | 93.57 (18.07) | 0.004 |
| | Better communication skills [b] | 82 | 102.94 (18.55) | |
| | Poorer communication skills [b] | 68 | 93.03 (16.75) | <0.001 |
| | Better community skills [b] | 82 | 103.07 (16.37) | |
| | Poorer community skills [b] | 68 | 92.87 (19.22) | <0.001 |

*Note.* WA, Western Australia, GP, General Practitioner, ADL; Activities of Daily Living

[a] Count of previous 12 months

[b] Continuous variables separated at median score

Table 11: Univariate relationships between Beach Centre Family Quality of Life Score (BCFQOL) and family factors

| Family factors | | Number | BCFQOL mean (SD) | P-value |
|---|---|---|---|---|
| Annual Family Income | $72800 and above | 51 | 103.11 (13.11) | |
| | Between $33800 and $72799 | 28 | 96.16 (17.16) | |
| | Less than $33799 | 26 | 90.48 (23.74) | 0.010 |
| | Chose not to answer | 36 | NA | |
| | Missing | 9 | NA | |
| Maternal age (years) | 37-45 | 10 | 95.20 (16.84) | |
| | 46-55 | 71 | 98.55 (18.64) | |
| | 56 and older | 69 | 98.81 (18.53) | 0.847 |
| Paternal age (years) | 39-45 | 8 | 96.5 (13.89) | |
| | 46-55 | 55 | 101.97 (16.96) | |
| | 56-65 | 56 | 96.27 (17.81) | |
| | 66 years and older | 20 | 100.82 (16.88) | 0.332 |
| Maternal education | Some high school | 39 | 98.98 (18.31) | |
| | High school completed | 31 | 98.81 (20.05) | |
| | Trade/advanced diploma | 32 | 97.21 (17.56) | |
| | Bachelor degree | 20 | 95.39 (17.48) | |
| | Graduate diploma | 19 | 99.64 (21.22) | |
| | Postgraduate degree | 5 | 97.05 (12.62) | 0.979 |
| | Unknown | 4 | NA | |
| Paternal education | Some high school | 28 | 100.37 (19.14) | |
| | High school completed | 20 | 101.14 (16.74) | |
| | Trade/advanced diploma | 41 | 98.63 (19.24) | |
| | Bachelor degree | 21 | 94.36 (15.31) | |
| | Graduate diploma | 12 | 97.72 (13.40) | |
| | Postgraduate degree | 15 | 98.42 (19.06) | 0.862 |
| | Unknown | 13 | NA | |
| Maternal work status | Not working | 49 | 95.67 (20.72) | |
| | Part-time work | 58 | 100.28 (16.62) | |
| | Full-time work | 35 | 97.06 (18.23) | |
| | Unknown | 8 | NA | 0.421 |
| Paternal work status | Not working | 21 | 95.27 (19.21) | |
| | Part-time work | 17 | 101.94 (14.70) | |
| | Full-time work | 85 | 99.73 (17.52) | 0.462 |
| | Unknown | 27 | NA | |
| Mother's occupation | 1 - Managers | 30 | 94.08 (16.35) | |
| | 2-Professionals/technicians/ trades workers | 14 | 101.47 (18.95) | |
| | 3- Community/Personal Service workers | 47 | 99.76 (17.53) | 0.283 |
| Father's occupation | 1 - Managers | 43 | 100.23 (17.36) | |
| | 2-Professionals/technicians/ trades workers | 12 | 99.89 (19.10) | |
| | 3- Community/Personal Service workers | 20 | 102.52 (14.48) | 0.866 |
| Presence of partner | Yes | 122 | 100.28 (16.94) | |
| | No | 26 | 89.85 (22.99) | 0.009 |
| Family supports[a] (Family Supports Scale) | Less supportive | 67 | 91.12 (18.91) | |
| | More supportive | 83 | 104.36 (15.71) | <0.001 |
| Informal assistance needs[a] (Family Needs Scale) | Lower assistance needs | 68 | 104.08 (18.82) | |
| | Higher assistance needs | 82 | 93.78 (16.73) | <0.001 |

*Note.* BCFQOL, Beach Centre Family Quality of Life Score

[a] Continuous variables separated at median score

(mean 91.12 SD 18.91) (Table 11). Also, families with lower assistance needs reported better family quality of life (mean 104.07 SD 18.82) than those with higher assistance needs (mean 93.78 SD 16.73).

Examination of the family quality of life subscale scores indicated that families were most satisfied with their Physical/Material wellbeing (mean 4.18 SD 0.73) and least satisfied with Emotional wellbeing (mean 3.47 SD 1.00), t(180)=12.04, p<0.001)(Table 12).

*Relationships between family quality of life and post-school day occupations*

Step one of the regression model adjusted for age, gender, family income, and mothers' and fathers' work status. Compared to families in the baseline group, (families of those attending open employment), families of those attending sheltered employment (coeff -9.38, 95%CI -17.66, -1.11) or day recreation programs (coeff -11.29, 95%CI -20.12, -2.26) reported lower family quality of life (Table 13). Step two of the regression model included levels of young person behaviour and their functional abilities. Compared to those in open employment, these variables accounted for the variance in the outcome for families of those attending day recreation programs (coeff -1.56, 95%CI -10.40, 7.29). Families of young people attending sheltered employment continued to report lower family quality of life (coeff -6.78, 95%CI -14.38, 0.81) than families of those attending open employment, however the strength of this relationship was reduced. At step three, the effect of lower family quality of life for families of young people attending sheltered employment compared to those attending open employment was slightly reduced again when taking into account family supports and informal assistance needs (coeff -6.00, 95%CI -12.76, 0.76).

*Influence of activities of daily living on the relationship between family quality of life and day occupations*

The inclusion of functional skills in step two of the regression model significantly influenced the outcome. Better functioning in ADL was associated with better family quality of life (coeff 0.45, 95%CI 0.05, 0.85)(Table 13). However the introduction of family supports and informal assistance needs in step three of the model, reduced the influence of functional abilities (coeff 0.29, 95%CI -0.10, 0.67).

A response to the open ended question asking the reason why the young person was not participating in their desired day occupation was provided by 64 families. Responses were coded into themes as shown in Table 14. The themes included extrinsic factors (eg. no jobs available or policy restraints) or intrinsic factors (young adults health or other personal reasons) that influenced participation in day occupation. The theme of lack of available and suitable jobs as a reason their young adult was not currently participating in their most desired day occupation was cited by almost half of the families.

## 5.5 Discussion

We found that families of young people participating in open employment reported better family quality of life than those in sheltered employment regardless of personal factors, although presence of family supports reduced this effect. We also found that families of young people who were functioning better in activities of daily living were more likely to report higher family quality of life.

The finding of better family quality of life for families of those attending open employment is important given that the young people we categorized as attending open employment may have spent as little as two hours a week in open employment, supplementing this time with attendance at other day occupations. Therefore, a small amount of time in open employment was associated with better

Table 12: Mean subscale scores of the Beach Centre Family Quality of Life (BCFQOL) by day occupation (n=150)

| | Open employment (n=38) | Training (n=16) | Sheltered employment (n=59) | Day recreation programs (n=37) | Total (n=150) | P-value |
|---|---|---|---|---|---|---|
| BCFQOL Subscales | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) | |
| Family interaction | 4.34 (0.58) | 4.18 (0.89) | 3.99 (0.72) | 3.88 (1.02) | 4.07 (0.81) | 0.068 |
| Parent interaction | 4.38 (0.63) | 4.01 (0.90) | 3.73 (0.72) | 3.73 (0.72) | 3.92 (0.86) | <0.001 |
| Emotional wellbeing | 3.78 (0.88) | 3.78 (1.10) | 3.39 (0.89) | 3.23 (1.18) | 3.49 (1.00) | 0.051 |
| Physical/material well -being | 4.46 (0.60) | 4.38 (0.71) | 4.06 (0.65) | 4.01 (0.85) | 4.19 (0.72) | 0.013 |
| Disability related support | 4.34 (0.57) | 4.20 (0.59) | 3.68 (0.81) | 3.67 (1.04) | 3.90 (0.85) | <0.001 |

*Note.* Range of subscales 0-5

*Note.* Items were rated on a 5 point scale and subscale scores were calculated as the mean score of all items in the subscale.

Table 13: Staged regression model of the relationships between day occupations, activities of daily living and the Beach Centre Family Quality of Life (BCFQOL) scores, accounting for person and environment variables

| | | Model Adjusted | | | | | |
|---|---|---|---|---|---|---|---|
| | | Step 1[a] (n=111) | | Step 2[b] (n=109) | | Step 3[c] (n=102) | |
| | | Coefficient (95%CI) | p-value | Coefficient (95%CI) | p-value | Coefficient (95%CI) | p-value |
| Day occupations | Open employment | Baseline | | Baseline | | Baseline | |
| | Training | -1.25<br>(-13.61, 1.10) | 0.841 | 0.12<br>(-10.86, 11.10) | 0.982 | 1.95<br>(-7.61, 11.50) | 0.686 |
| | Sheltered employment | -9.38<br>(-17.66, -1.11) | 0.024 | -6.78<br>(-14.38, 0.81) | 0.079 | -6.00<br>(-12.76, 0.76) | 0.081 |
| | Day recreation programs | -11.29<br>(-20.12, -2.26) | 0.013 | -1.56<br>(-10.40, 7.29) | 0.728 | 0.92<br>(-7.12, 8.97) | 0.820 |
| Functioning in ADL | | - | - | 0.45<br>(0.05, 0.85) | 0.027 | 0.29<br>(-0.10, 0.67) | 0.141 |

*Note.* Coefficients show the change in the BCFQOL score by independent variables

*Note.* BCFQOL, Beach Centre Family Quality of Life Scale

[a] Step 1: Age, gender, family income, mothers work status, fathers work status
[b] Step 2: Level of functioning, young person behaviour
[c] Step 3: Family supports and informal supports

Table 14: Themes and sample quotes reported by families on factors influencing young adults participation in day occupations (n=64 total phrases)

| | Themes n, % of phrases | Quotes illustrating themes |
|---|---|---|
| Extrinsic factors (n=43, 67.2%) | No appropriate or suitable open employment jobs available (n=28, 43.8%) | “Open employment is very hard to find, and agencies do not seem to offer full time employment and there is not an option to work part time in two different jobs”<br>“Open work virtually impossible to obtain.”<br>“Cannot find a suitable job within reasonable travel time. Lots of promises but nothing fruitful.” |
| | Policy, funding or service provider constraints (n=11, 17.2%) | “Would like open employment but can't look for a job while already working in business service (sheltered employment). However, this is the problem - it is too risky to stop work and look for job in open employment as we may not find anything suitable. Then there is no job at all. While working in a business service provides security and mentoring on the job, it is a closed situation and the pay is insulting.”<br>“The organization providing support for people with disabilities in rural areas is not quite adequate” |
| | Family reasons (parents work situation, availability of time) (n=5, 7.8 %) | “Post-school options and open work does not fit ours and our daughters availability, it is irregular/not reliable.”<br>“Timing of work shifts…” |
| | Health reasons (n=5, 7.8%) | “Our daughter's eyesight impinges on her choices. Specialist was shocked when I mentioned independent public transport - too dangerous”<br>“Has developed early onset Dementia – He has violence issues” |
| Intrinsic factors (n=21, 31.8%) | Personal volition (n=8, 12.5%) | “Just waiting for him to get used to working, then will begin to look for open employment, may be one year”<br>“He loves his work and friends. Gets very tired though. He needs some social time for life skills” |
| | Lack of skills to undertake employment (n=4, 6.3%) | “Her lack of skills makes it difficult to secure open employment.”<br>“As she has limited communication, it is not feasible for her to be in an open work environment or even attending TAFE without someone watching out for her. The sheltered workshop although not my ideal, it would appear to be an environment she is comfortable in. She is happy to be with her peers, not so much in age, but perhaps in ability.” |
| | Content with current situation (n=4, 6.3%) | “Our son is extremely happy in his current workplace and that is all I wish for him.”<br>“He is very happy and comfortable in the business services (sheltered employment) environment but ideally I would like to see him in open employment” |

family quality of life. Participation in open employment for people with intellectual disabilities in Australia has not changed in the last four years and during the ten years prior, there were only small increases in the rate of participation (Tuckerman et al., 2012). In contrast, proportions of people participating in sheltered employment and day recreation programs have continued to increase (Tuckerman et al., 2012). Previous Australian research suggested that young people with intellectual disability who were in open employment reported higher individual quality of life than their unemployed counterparts (Eggleton, Robertson, Ryan, & Kober, 1999). However this research did not investigate the quality of life of young people attending day occupations other than open employment. Our study is also the first to investigate the quality of life of families of young people attending a variety of day occupations and to account for the influence of other personal, family and environmental factors. Our findings illustrate the importance of giving young people with Down syndrome, and likely others with similar levels of intellectual disability, the opportunity to be employed at the best of their potential – in open employment – even if only on a part time basis, and provide important information to guide employment policy.

Assistance required for activities of daily living is now considered in the diagnosis of intellectual disability and the level of assistance has a relationship with the type of day occupations young people with Down syndrome attend (Foley et al., 2013; Schalock et al., 2010). In this study, we found that families of those young people with better functioning in self-care, community and communication skills reported better quality of life. After adjusting for family characteristics, the association between functional ability and family quality of life was weakened. Of concern, other studies have identified a decline in self-care skills, an important sub-domain of functioning in ADL, in adulthood for people with Down syndrome (Esbensen, Seltzer, & Krauss, 2008; Rasmussen & Sobsey, 1994). Our previous study found that higher level functioning in ADL was strongly associated with increased likelihood of participating in open employment or training post-school (Foley et al., 2013). That study and the findings from this present study suggest that development of daily living skills, during childhood and adolescence has the potential in adulthood to have a positive influence on family quality of life. Increased emphasis on provision of training in these skills during childhood and adolescence should therefore be a key focus of services working with children and adolescents with an intellectual disability.

The presence of family and community supports and less informal assistance needs was associated with better family quality of life. Such supports reduced the relationship between day occupations and family quality of life. Previous research with families of preschool children with developmental delay or disability found that positive perceptions of professional support by parents were one of the strongest predictors of family quality of life (Davis & Gavidia-Payne, 2009). Similar to findings from other research (Brown, Anand, Fung, Isaacs, & Baum, 2003) these authors also found that support from extended family members and the intensity of child behavioural problems accounted for variance in the family quality of life outcome (Davis & Gavidia-Payne, 2009). The influences of family and community support continue to be vitally important ingredients of family quality of life as children with intellectual disability transition into adulthood.

The inherent challenges with measuring family quality of life were a limitation in this study. A parent or guardian completed the questionnaires resulting in their perspective of the quality of the family's life. Research has shown that mothers and fathers may have differing perspectives on what influences the family quality of life including family functioning, life stressors and sources of support (Park et al., 2003; Crowley, & Taylor, 1994). Future research should focus on further developing measures of family quality of life to include multiple perspectives and identify appropriate statistical techniques to analyses these data in a meaningful way.

Another potential limitation was the influence of missing data. Participant responses were not included if there were more than three missing items on the scale minimizing the influence of incomplete responses. It should be noted that there was a notably high response fraction in the Down syndrome NOW study which ensures a representative sample with minimal bias (Bourke et al., 2009; Foley et al., 2013).

Qualitative research undertaken in Australia with families of adolescents with a severe intellectual disability has illustrated the dynamic nature of family routines and found that families faced many internal and external challenges (Schneider et al., 2006). Parents of young people with Down syndrome also acquire a number of additional roles including advocate, teacher and parent-group leader (Scorgie & Sobsey, 2000). This study has presented parents views of factors influencing young adult's participation in post-school day occupations. The majority of parents cited extrinsic barriers to gaining employment such as availability of jobs, policy or funding constraints, and parental lack of availability of time. Family efforts to maintain a meaningful family routine, manage extra roles and face internal and external challenges as their son or daughter enters post-school occupations have the potential to influence overall family quality of life. Our research has identified that participation in open employment is another factor which could positively influence family quality of life and parents views on external barriers to accessing open employment in the post-school years.

## Preface to chapter six

The complex relationship between activities, elements of the environment and participation in day occupation for young adults with Down syndrome have been explored in the previous two chapters. The next chapter explores the relationship between behaviour changes and day occupation. Behaviour can be categorised within the mental functions chapter of the ICF which is part of the body functions and structures component.

This manuscript has been accepted for publication in *BMC Psychiatry*.

The PhD Candidate, Kitty-Rose Foley accounted for 85% of the intellectual property associated with the final manuscript. Collectively, the remaining authors contributed 15 per cent.

# Chapter 6: Behaviour changes and participation

## DAY OCCUPATIONS ARE ASSOCIATED WITH PSYCHOPATHOLOGY FOR ADOLESCENTS AND YOUNG ADULTS WITH DOWN SYNDROME

### 6.1 Abstract

Background: Young adults with Down syndrome experience increased rates of emotional and behavioural problems compared with the general population. Most adolescents with Down syndrome living in Western Australia participate in sheltered employment as their main day occupation. The relationship between day occupation and changes in behaviour has not been examined. Therefore, the aim of this research was to explore any relationship between post-school day occupations and changes in the young person's behaviour.

Methods: The Down syndrome Needs Opinion Wishes database was used for case ascertainment of young adults aged 15 to 32 years with Down syndrome. Families of 118 young people in this population-based database completed questionnaires in 2004, 2009 and 2011. The questionnaires addressed both young person characteristics such as age, gender, presence of impairments, behaviour, functioning in activities of daily living, and family characteristics such as income and family functioning. Post-school day occupations in which the young people were participating included open and sheltered employment, training and day recreation programs. Change in behaviour of young adults who remained in the same post-school day occupation from 2009 to 2011 (n=103) were examined in a linear regression model adjusting for confounding variables including age, gender functioning and behaviour in 2004 and family income.

Results: In comparison to those young adults attending open employment from 2009 to 2011, those attending day recreation programs were reported to experience worsening in behaviour both in the unadjusted (coeff -0.14, 95%CI -0.24, -0.05) and adjusted models (coeff -0.15, 95%CI -0.29, -0.01).

Conclusions: We found that the behaviour of those participating in open employment improved compared to those attending other day occupations. Further examination of the direction of this association is required.

## 6.2 Introduction

People with intellectual disabilities are at a higher risk of experiencing behavioural, emotional and psychiatric problems than the general population (Dykens, 2007; Einfeld & Tonge, 1996; Paschos & Bouras, 2007). In an Australian study, approximately 40 percent of young people with intellectual disability aged 4 to 18 years were found to have severe emotional and behavioural disorders with a subsequent longitudinal study finding that psychopathology persisted over time (Einfeld et al., 2006; Einfeld & Tonge, 1996). People with Down syndrome have been reported to experience fewer behavioural and emotional disturbances than others with intellectual disability (Cooper & Speck, 2009; Mantry, Cooper, Smiley, Morrison, & Allan, 2008), yet still more than the general population (Fidler, Most, Booth-Laforce, & Kelly, 2006). Examination of age-related changes in behaviour of children and young people with Down syndrome revealed that externalising behaviours (dominant, opposing, impulsive) were more common in five to ten year olds and internalising behaviours (lacking in self-confidence/shy and insecure) more common in adolescents and adults (10 to 30 years)(Nicham et al., 2003).

Behaviour problems have been found to be associated with poorer outcomes for young people with intellectual disability and to have a negative impact on social participation. Those with more behaviour problems are reported to be more likely to have activity limitations in communication, self-care and community skills (Danquah et al., 2009; Foley et al., 2013; Papazoglou, Jacobson, & Zabel, 2013). They were also more likely to have difficulties forming and maintaining friendships and to spend fewer hours in education each month (Farmer, 2000; White & Dodder, 2000). Moreover, poorer family outcomes have been reported for the families of those who have more behavioural problems. These include poorer family quality of life, family functioning and poorer maternal mental health (Bourke et al., 2009; Foley et al., 2014; Glidden, 2012; Hastings & Beck, 2004; Povee et al., 2012; Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011).

According to social learning theory behaviour is learned through modelling, observing and imitating others (Bandura, 1977, 1986). One such place where this modelling, observing and imitating can occur is a person's social environment within the workplace. Young people with intellectual disability who participate in different day occupations have varied opportunities to model, observe and imitate behaviours from peers (Wuang & Chwen-Yng, 2012). Theorists have highlighted how changes in life-course, such as transitions, can impact on behaviour (United Nations, 2012). They discuss how relationships with peers and parents and participation in activities such as post-school day occupations can positively or negatively influence behaviour. The different day occupations in which young people with intellectual disability participate provide varied social environments and opportunities for modelling of behaviour, participating in activities and forming relationships with peers. These factors all have the potential to positively or adversely influence change in behaviour for young people with Down syndrome.

Post-school day occupations for young people with intellectual disability in Australia include the following; open employment, i.e. work in a mainstream setting often with support; training, i.e. further education such as Technical and Further Education (TAFE); sheltered employment, i.e. work in a segregated setting for people with disabilities currently referred to as 'Australian Disability Enterprises' in Australia; Alternatives to Employment (ATE), i.e. a day recreation program specifically designed for people with disabilities who are unable to participate in employment or further training or; remaining at home with family or peers (Foley et al., 2013). According to the Australian Institute of Health and Welfare in 2011 people with intellectual disabilities constitute 30% of the users of disability support services in Australia with 76% of those being under the age of 45 years (Australian Institute of Health and Welfare., 2010-11). They are able to access one of two government employment services 1) open employment services to access paid employment in the open labour market or 2) ‘supported employment’ services to access sheltered employment. Of all those who access the open employment services only 12% had an intellectual disability compared to 69% of those accessing the ‘supported employment’ services. Expenditure on disability support services has increased since 2005-2006, specifically community support services (by 80%) and employment support services (by 47%). Over the past ten years the participation of young people with intellectual disability in sheltered employment has increased by 25%. Participation in state government funded community access non-work programs such as ‘Alternatives to Employment’ (ATE) has also increased by 18%. However, the number of young people with intellectual disability participating in open employment has remained stagnant over this same time period (Tuckerman et al., 2012), regardless of the reported 47% increase of expenditure on employment services since 2005 (Australian Institute of Health and Welfare., 2010-11).

Identifying behaviour management strategies to reduce stress and enhance wellbeing for young people with Down syndrome has been highlighted as an important focus for research (Dykens, 2007) (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Smiley, 2005). We know that the social environment can influence the behaviour of typically developing people (Wuang & Chwen-Yng, 2012), suggesting that the behaviour of young people with Down syndrome may also be influenced by different social environments, including different day occupations (e.g. sheltered employment versus open employment). Therefore, the aim of our research was to explore the relationship between post-school day occupations and young person’s change in behaviour over a two year period. We hypothesised that those participating in open employment behaviour would improve more than those participating in the other day occupations.

The International classification of functioning, disability and health (ICF) is an internationally recognised framework for classifying health conditions, health related states and health outcome measurement (World Health Organization, 2001). Its usefulness for research in the field of intellectual disability has been well recognized (Arvidsson, Granlund, & Thyberg, 2008; Foley, Dyke, et al., 2012; Foley et al., 2013; Jelsma, 2009; Verdonschot et al., 2009b). Investigating complex experiences such as the relationship between behaviour and participation in day occupations taking into account the influence of environmental factors can present challenges. As a result of this, we have used the ICF to frame this study in order to examine these complex associations.

## 6.3 Methods

The Down syndrome "Needs Opinions Wishes" database is a population-based source of young people with Down syndrome residing in Western Australia. This study focused on young people, ascertained from this database, aged 15 to 32 years in 2009, whose parents completed questionnaires during the period 2004 to 2011. Data collection occurred at three time points: 2004, 2009 and 2011 (response fractions were 73%, 89%, 93%, respectively). Only those young adults who were post-school in 2009 (n=164) and 2011 (n=180) were included in this study as we were interested in the relationship between post-school occupations and behaviour. Ethics approval for this study was sort through both the Human Research Ethics Committee of Edith Cowan University and the Princess Margaret Hospital for Children Ethics Committee. There were 118 families who returned the questionnaire at all three time points and whose sons and daughters were post-school in 2009 and 2011.

Data were collected in the form of questionnaires containing two parts. Part one pertained to the young person's characteristics including age, gender, behavioural problems and functioning in activities of daily living (ADLs) and part two asked about family characteristics. The measures which were included in the questionnaire and are relevant for this study are classified within the components of the ICF. The relationships between the measures and the specific codes of the ICF for each component are shown in Figure 3.

*Body functions and structures:* Behavioural and emotional problems were measured using the parent report Developmental Behaviour Checklist (DBC), the 96-item child version in 2004 (DBC-C) (Einfeld & Tonge, 1995) and the 107-item adult version in 2009 and 2011 (DBC-A) (Mohr et al., 2011). The DBC was specifically developed for people with developmental and intellectual disabilities with each behavioural response being scored 0 (not true as far as you know), 1 (somewhat or sometimes true) or 2 (very true or often true). The DBC-C has proven convergent validity, high inter-rater reliability between teachers and parents, high test-retest reliability and sensitivity to change (Einfeld & Tonge, 1995). The DBC-A has been found to have acceptable test-retest and inter-rater reliability and convergent ability has been demonstrated with two measures of behavioural disturbances of adults with intellectual disability (Mohr, Tonge, & Einfeld, 2005).

The DBC-A and DBC-C were scored in three ways for this study which enables them to be comparable (Taffe, Tonge, Gray, & Einfeld, 2008); 1) Mean Item Score (MIS) reflecting the overall behaviour problems 2) Proportion of Items Checked (PIC) which is the proportion of items checked a one or a two and measures range of problem behaviours exhibited, 3) the Intensity Index (II) which is the proportion of items checked 2, out of all the items checked 1 or 2 which measures the severity of the problem behaviours. The DBC-A contains 12 new items and drops one from the DBC-C. To maximize comparability of scores between the two versions, the adult measure was scored using the child factors as suggested by the developers of the measure (Einfeld et al., 2006). The majority of questionnaires were completed by the young person’s mother across the three time points.

*Activity:* In the 2004 questionnaires, an adjusted paediatric Functional Independence Measure (WeeFIM) was included to measure functioning in activities of daily living (Msall et al., 1994). The WeeFIM has been well validated in cohorts of children with different developmental disorders, including Down syndrome. It has been used in individuals up to 25 years of age (Colvin, Leonard, De Klerk, Davis, Weaving et al., 2004). The WeeFIM has good inter-rater reliability and concurrent validity with the Pediatric Evaluation of Disabilities Inventory in children with developmental disabilities (Ziviani et al., 2001). The adjusted score relates to its modification for questionnaire use, as has been described in previous studies (Leonard, Msall, Bower, Tremont, & Leonard, 2002). Piloting the questionnaires confirmed the WeeFIM was appropriate for participants of this wave of data collection.

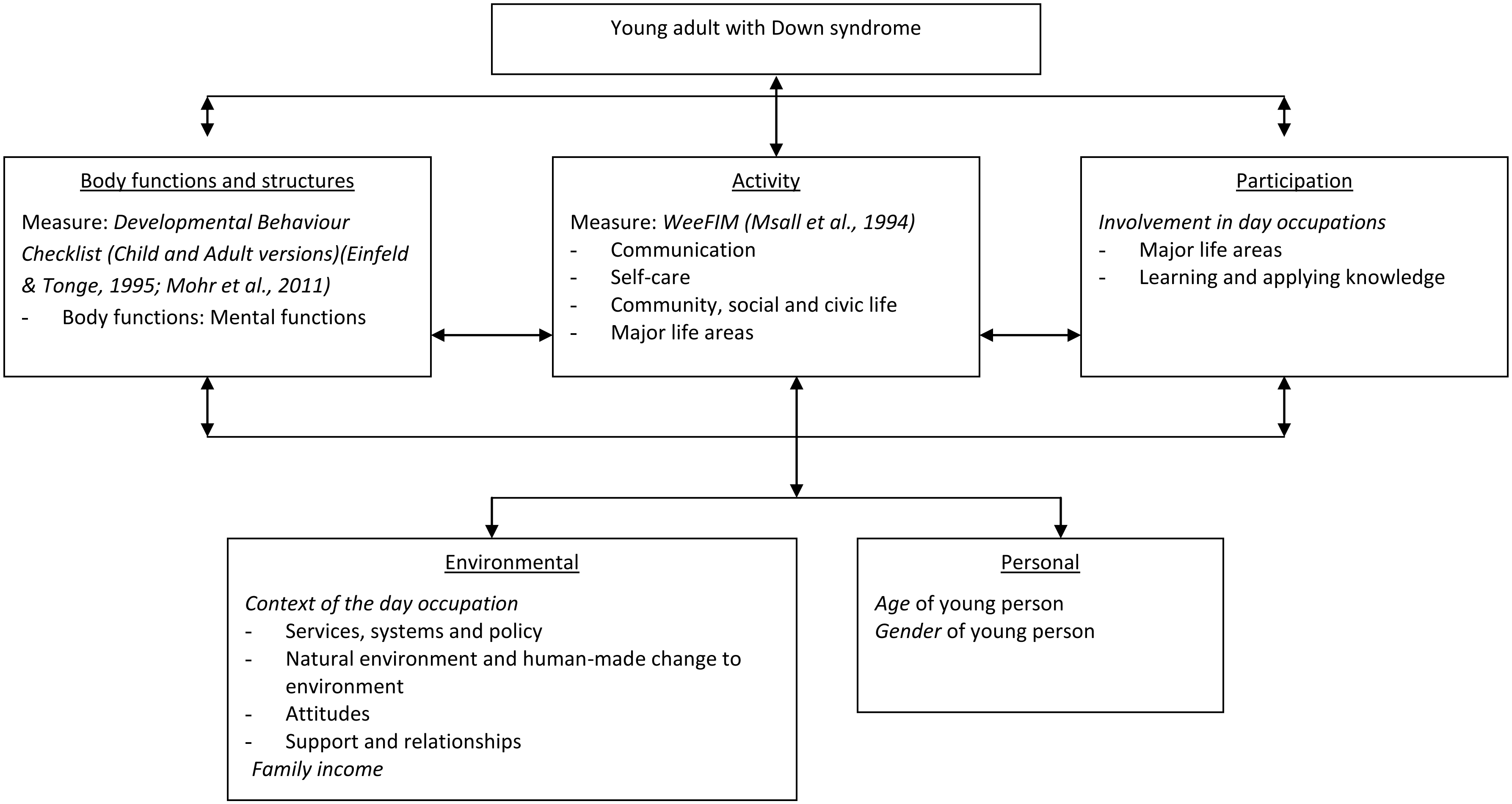
*Participation and environmental factors:* Day occupations are one aspect of the participation component of the ICF, identifying involvement in different occupations. They are also associated with environmental factors, as the social and physical environment of the occupation could influence the young adults. For example, presence of support and relationships with colleagues at the day occupation may influence the individual's behaviour. Post-school day occupations in which the young adults were participating in 2009 and 2011 were categorised according to open employment, training, sheltered employment or day recreation programs described as Alternatives to Employment (ATE) programs.

*Personal factors:* Personal factors including age and gender of the young adult with Down syndrome were ascertained from the database.

### 6.3.1 Data analysis

Descriptive statistics including analysis of variance and chi-squared tests were used to describe the univariate relationship between independent variables and the outcome, change in problem behaviours from 2009 to 2011. Descriptive statistics

Figure 3: Methodology model as per ICF framework: Second level classifications which are assessed within the ICF components



were also used to describe the problem behaviour scores at each time point across the different post-school day occupations.

Change in behavior was the main outcome and was the difference in the 2009 and 2011 DBC behaviour scores. A linear regression model with change in behaviour from 2009 to 2011 as the outcome was used in the final model allowing adjustments for confounding variables. These included; age, gender, family income, functioning in activities of daily living at baseline and problem behaviour score at baseline. Functioning in ADL and behaviour at baseline were included in the linear regression model as confounding variables to account for young people having different levels of behaviour problems and functioning levels prior to engaging in their post-school day occupations. Unadjusted and adjusted models were reported separately. STATA 11 was used for these analysis (Statacorp, 2003).

## 6.4 Results

### 6.4.1 Participant characteristics

The ages of the 118 young people whose parents returned questionnaires across all three time points ranged from 10 to 24 years in 2004 (mean 17.2 SD 4.3). Of these 118, 51 (43.2%) were female and 67 (56.8%) were male.

### 6.4.2 Relationship between post-school day occupations and change in behaviour problems

The day occupations of all young adults, who returned a questionnaire in 2009 and/or 2011, are shown in Table 15. Young adults who remained in the same day occupation over these two time points are shown (n=103/164, 64%). Of the 103 young adults who remained in the same day occupations from 2009 to 2011, those attending day recreation programs were reported as having the poorest behaviour in 2009 in terms of range (PIC) (mean 0.30 SD 0.16), intensity (II)(mean 0.38 SD 0.21) and overall score (MIS)(mean 0.41 SD 0.25). From 2009 to 2011, the range (PIC (t(21)= -2.49, p=0.02)) and overall score (MIS (t(21)= -1.98, p=0.06) of behaviour problems of young adults participating in day recreation programs increased but the intensity (II (t(21)=0.39, p=0.70)) remained relatively stable (Table 16). In 2011, 45.5% (n=10) of the young adults attending day recreation programs reported MIS scores beyond the cut-off point for psychiatric caseness, meaning a full psychiatric assessment is recommended (Mohr et al., 2011).

Young adults attending open employment in 2009 were reported as having the fewest behavioural problems in terms of range (PIC (mean 0.14, SD 0.11)) and overall score (MIS (mean 0.16 SD 0.13)) and those attending training had the lowest intensity (II (mean 0.12 SD 0.15)) of behavioural problems. The range (PIC(t(26)=2.07, p=0.049)) and overall (MIS (t(26)=2.58, p=0.016)) scores for those attending open employment decreased significantly from 2009 to 2011. The range (PIC (t(45)=1.78, p=0.08)), intensity (II (t(44)=0.87, p=0.54)) and overall score (MIS (t(45)=1.61, p=0.11)) for behaviour problems in those attending sheltered employment showed a similar but not significant trend to decrease from 2009 to 2011 (Table 16).

### 6.4.3 Adjusted model

Change in behaviour from 2009 to 2011 was converted to a change score for the regression model, where a positive number referred to an improvement in behaviour (Table 17). Confounding variables which were adjusted for included age in 2004, gender, family income, functioning in activities of daily living (ADL) in 2004 and problem behaviours (DBC continuous score) in 2004. The coefficients in the table reflect a per point change in overall behaviour MIS compared to the change in behaviour of those attending open employment. In comparison to those young adults attending open employment from 2009 to 2011, those attending day recreation programs experienced significant worsening in behaviour both in the

Table 15: Day occupations of all young adults who were post-school and returned questionnaires in 2009 and/or 2011

| Day Occupation | 2009 (%) | 2011 (%) | Remained |
|---|---|---|---|
| Open employment | 42 (25.6) | 40 (22.2) | 27 (26.2) |
| Training | 17 (10.4) | 23 (12.8) | 8 (7.8) |
| Sheltered employment | 64 (39.0) | 75 (41.7) | 46 (44.7) |
| Day recreation programs | 41 (25.0) | 38 (21.1) | 22 (21.4) |
| Remained at home | 0 (0) | 4 (2.2) | - |
| Total | 164 (100) | 180 (100) | 103 (100) |

Table 16: Mean problem behaviour scores in 2009 and 2011

| | | Problem Behaviour Scores | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Proportion Items Checked (range of behaviour problems) | | | Intensity Index (severity of behaviour problems) | | | Mean Item Score | | |
| Day Occupations | Freq | 2009 M, SD | 2011 M, SD | p-value | 2009 M, SD | 2011 M, SD | p-value | 2009 M, SD | 2011 M,SD | p-value |
| Open | 27 | 0.14, 0.11 | 0.11, 0.10 | 0.049 | 0.15, 0.16 | 0.10, 0.22 | 0.317 | 0.16, 0.13 | 0.11, 0.10 | 0.016 |
| Training | 8 | 0.19, 0.15 | 0.22, 0.05 | 0.446 | 0.12, 0.15 | 0.15, 0.13 | 0.173 | 0.22, 0.21 | 0.25, 0.18 | 0.574 |
| Sheltered | 46 | 0.20, 0.15 | 0.17, 0.13 | 0.081 | 0.21, 0.20 | 0.19, 0.19 | 0.535 | 0.25,0.19 | 0.21, 0.17 | 0.114 |
| Day recreation programs | 22 | 0.30, 0.16 | 0.36, 0.12 | 0.021 | 0.38, 0.21 | 0.38, 0.24 | 0.982 | 0.41,0.25 | 0.50,0.35 | 0.061 |

*Note.* Higher behaviour score refers to poorer behaviour from 2009 to 2011

*Note.* Cut-off score for psychiatric caseness Mean Item Score =0.48

unadjusted (coeff -0.14, 95%CI -0.24, -0.05) and adjusted models (coeff -0.15, 95%CI -0.29, -0.01)(Table 17).

We examined the change in behaviour of the young adults who were in open employment and day recreation program at the 2009 time point but were not in the same occupation in 2011. We were interested to see the behaviour change patterns of those young adults who did not remain in the same day occupation. We found that there was no significant difference for those who remained in open employment (mean change 0.05, SD 0.10) and those that changed from open employment to a different day occupation (mean change -0.02 SD 0.17)(p-value=0.14). However, there was a difference between the groups who remained in day recreation programs (mean change -0.09 SD 0.22) and those that changed out of day recreation programs into a different day occupation (mean change 0.05 SD 0.14)(p=0.05).

## 6.5 Discussion

Adolescents and young adults with Down syndrome attending open employment for two consecutive years were found to experience a decline in behaviour problems in terms of range, intensity and overall problems, after adjusting for known confounding variables. Those attending sheltered employment for two years also experienced a decline in problem behaviours in range, intensity and overall behaviour problems, but this was less marked than for those in open employment. Young adults who were attending day recreation programs for two years experienced an increase in range, intensity and overall behaviour problems. At the second time point almost half of these young adult's behaviour problems were reported to be beyond the clinical cut-off score for psychiatric caseness (Mohr et al., 2011).

Table 17: Linear regression model of behaviour change scores from 2009 to 2011 by day occupation

| | | Unadjusted (n=103) | | | Adjusted Model (n=69) | | |
|---|---|---|---|---|---|---|---|
| | | Coeff[a] | 95% CI | P value | Coeff | 95% CI | P Value |
| Mean Item Scores | Open employment | Baseline | | | Baseline | | |
| | Training | -0.08 | -0.21, 0.05 | 0.217 | -0.10 | -0.23, 0.04 | 0.152 |
| | Sheltered employment | -0.01 | -0.09, 0.06 | 0.728 | -0.01 | -0.10, 0.09 | 0.894 |
| | Day recreation programs | -0.14 | -0.24, -0.05 | 0.002 | -0.15 | -0.29, -0.01 | 0.034 |

*Note.* Variables in adjusted model: age, gender, family income (imputed variable), functioning in 2004, behaviour in 2004

*Note.* Positive behaviour score refers to an improvement in behaviour from 2009 to 2011.

[a] Coefficient reflects a per point change in the behaviour score in comparison with the reference group (open employment) changes in behaviour

A considerable strength of this paper is the use of the DBC to measure emotional and behavioural problems at three time points. The use of the child version and the adult version ensures that the questionnaire remains applicable and valid (Taffe et al., 2008). Scoring the range and intensity of emotional and behavioural problems adds a particularly clinically relevant interpretation of the data which could not be ascertained from only scoring the overall total (Taffe et al., 2008). It allows us to recognize the type of behaviour changes which then provides more detailed information to guide development of intervention. A limitation of this study relates to the fact that those young people who move out of open employment could do so because of deteriorating behaviour, which could contribute to the improved behaviour seen in the group who remain. However, when we investigated this we found that there was no difference in the changes in behaviour of those that remained and those that left open employment. However, we did find that for those who left the day recreation programs behaviour improved significantly in comparison to those who remained in day recreation programs. We cannot definitely state whether these young people's behaviour improved because they left the day recreation programs or they left because their behaviour improved. Another potential limitation of this study is that the data are parent report. Research in the general population has indicated that there may be discordance between parent and young person reporting of emotional and behavioural problems, specifically in regards to internalizing behaviours and when the parent experiences psychopathological issues (Ferdinand, van der Ende, & Verhulst, 2004; Hughes & Gullone, 2010; Treutler & Epkins, 2003). However, challenges gaining self-report data from young people with intellectual disability have been acknowledged and the need for appropriate and psychometrically rigorous instruments for young people with intellectual disability to report their own emotions and behaviours has been highlighted (Douma, Dekker, Verhulst, & Koot, 2006; Haynes, Gilmore, Shochet, Campbell, & Roberts, 2013). It is important to investigate the potential influence that participation in open employment could have on behavioural and emotional problems of young adults with Down syndrome. Although, we cannot definitively confirm any causal relationship between day occupations and changes in behaviour over time, our study would suggest that further scrutiny of this association is needed.

We found that participation in open employment was associated with an improvement in behaviour over time compared to other day occupations. This association could be attributed to many different factors such as the modeling of positive behaviours from typically developing peers or the satisfaction of participation in a meaningful, mainstream occupation. The idea that the behavior of young people who are attending open employment improves as a result of modeling, observing and imitating the behavior of their typically developing peers is supported by Bandura's theory of social learning (Bandura, 1977). Research has shown that young people with intellectual disability who participate in open employment experience greater perceptions of job clarity and are provided more opportunities for socialization than those participating in day recreation programs or sheltered employment (Beyer, Brown, Akandi, & Rapley, 2010; Hall & Kramer, 2009). Previous research has already shown that there are positive associations between participation in open employment and social and activity related outcomes and that young people with intellectual disability have a desire to have the opportunity to participate in the open labour market (Migliore, Mank, Grossi, & Rogan, 2007; Scott et al., 2013). Despite this evidence and the significant increase in expenditure on employment services for people with disabilities in Australia, there has been no change in the number of people with intellectual disability participating in open employment in Australia over the past ten years (Australian Institute of Health and Welfare., 2010-11; Tuckerman et al., 2012).

In relation to sheltered employment, our results showed a trend towards improving behaviour over the two year time period. Martorell, Gutierrez-Recacha, Pereda and

Ayuso-Mateos (2008) cross-sectionally examined behaviour of young people involved in sheltered employment and day recreation services and concluded that those participating in sheltered employment reported less problem behaviours compared to those attending day recreation services. However, people who were attending open employment were not included in their study and the authors proposed that behaviour problems prevent good functioning and cause a worse work outcome (Martorell, Gutierrez-Recacha, Pereda, & Ayuso-Mateos, 2008). We suggest that the direction of this relationship has not been proven and perhaps young people who have more problem behaviours could decrease problem behaviours through participation in open employment. In a further adjusted analysis Martorell and colleagues showed that the influence of behaviour was ameliorated by the inclusion of a variable describing self-determination. Self-determination has been reported to occur with more normalized, community-based environments for people with intellectual disability, such as an open employment context (Wehmeyer & Bolding, 2001; Wehmeyer & Palmer, 2003).

In our study the young adults who were attending day recreation programs for two consecutive years showed a concerning increase in range of problem behaviours and overall problem behaviours. This could be attributed to lack of choice-making opportunities, isolation and segregation from the community and lack of meaningful and challenging activities within the day recreation programs. These young adults showed a significant increase in range of problem behaviours but not intensity. This also suggests that the young adults who were attending day recreation programs may have modelled undesirable behaviours from their peers in the day recreation programs environment which would increase the range of problems they exhibit and not alter the intensity. Additionally, almost half of those young adults attending day recreation programs for two years had reported problem behaviour scores beyond the clinical cut-off for a psychiatric case. A comprehensive psychiatric assessment is recommended for those young adults who scored beyond the cut-off score (Mohr et al., 2011). The stated aims of day recreation programs include support outcomes related to social participation, increasing independence, lifelong learning and enhanced support networks (Disability Services Commission, 2009). Further examination of whether this occurs and the effectiveness of available strategies appears critical.

Framing this research within the ICF allows for investigation of the ICF components which have an association with change in behaviour for young people with intellectual disability. This research has highlighted the potential for environmental factors (i.e. context of the day occupations) to modify behavioural disturbances in young adults with Down syndrome. We cannot confirm the direction of the relationship between change in behaviour and day occupation. However our findings do raise specific questions about the potential mechanisms underlying these. We also found a trend towards decreasing problem behaviours for young adults who were attending sheltered employment compared to other day occupations. The main difference between a sheltered employment environment and a day recreation program environment is participation in an organized task and adherence to routines and clearly defined rules for safety, dress and behaviour. The increase in problem behaviours in those young adults participating in day recreation programs compared to those participating in sheltered employment suggests that the activity of undertaking specific tasks in the sheltered employment environment could be playing a role in decreasing problem behaviours for those young people. The sheltered employment environment could also create more opportunities for steady friendships which could have a positive influence on behaviour. These points highlight the relationship between the participation component of the ICF and the impairments of body functions and structures component. They also provide valuable information about the importance of environmental factors and participation when considering the psychopathology of young people with Down syndrome.

The problem of psychopathology has been reported as both substantial and persistent for young people with intellectual disability and the need for effective mental health interventions is paramount (Einfeld et al., 2006). This study has provided information which should be considered when developing mental health interventions for young people with Down syndrome. This study is one of the first, to the authors' knowledge, to investigate the relationship between behavioural change and specific post-school day occupations. The longitudinal nature of the study adds strength as well as the fact that case ascertainment occurred from a population-based database. The evidence from this study will be useful in designing intervention studies, as we have identified contexts (open employment settings) which could influence change in behaviour for young people with Down syndrome. Future research should focus on identifying the specific mechanisms within an open employment setting which could positively influence behaviour change.

## Preface to chapter seven

Elements of activities, body functions and structures and environmental factors have been investigated within this thesis. Participation in day occupations has been the main outcome of interest. Participation is a fluid concept which involves many elements and is difficult to accurately measure. The next chapter investigates participation in terms of participation in social roles and participation in daily activities for young adults with Down syndrome. This chapter also investigates the influence of different environmental factors on participation. The environmental factors component of the ICF includes not only family support (as addressed in chapter four) but also elements of the natural and man-made environment, attitudes of friends, colleagues, strangers and professionals, and services, systems and policies (World Health Organization, 2001). The influence of these environmental factors on participation in social roles and daily activities is investigated in the following chapter.

This manuscript has been accepted for publication in *PloS One.*

The PhD Candidate, Kitty-Rose Foley accounted for 85% of the intellectual property associated with the final manuscript. Collectively, the remaining authors contributed 15 per cent.

# Chapter 7: Social participation and influence of the environment

## INFLUENCE OF THE ENVIRONMENT ON PARTICIPATION IN SOCIAL ROLES FOR YOUNG ADULTS WITH DOWN SYNDROME

### 7.1 Abstract

Background: The concept of disability is now understood to result from the interaction between the individual, features related to impairment, and the physical and social environment. It is important to understand these environmental influences and how they affect social participation. The purpose of this study is to describe the social participation of young adults with Down syndrome and examine its relationship with the physical and social environment.

Methods: Families ascertained from the Down syndrome 'Needs Opinions Wishes' database completed questionnaires during 2011. The questionnaires contained two parts, young person characteristics and family characteristics. Young adults' social participation was measured using the Assessment of Life Habits (LIFE-H) and the influences of environmental factors were measured by the Measure of the Quality of the Environment (MQE). The analysis involved descriptive statistics and linear and logistic regression.

Results: Overall, engagement in daily activities, as measured by the LIFE-H, was higher (mean 6.45) than participation in social roles (mean 5.17) (range 0 to 9). When the physical and/or social environment was reported as a facilitator, compared to being no influence or a barrier, participation in social roles was greater (coef 0.89, 95%CI 0.28, 1.52, coef 0.83, 95%CI 0.17, 1.49, respectively). The relationships between participation and both the physical (coef 0.60, 95% CI -0.40, 1.24) and social (coef 0.20, 95%CI -0.47, 0.87) environments were reduced when age, gender, behavior and functioning in ADL were taken into account.

Conclusion: We found that young adult’s participation in social roles was influenced more by the physical environment than by the social environment, providing a potentially modifiable avenue for intervention.

## 7.2 Introduction

According to the World Health Organisation (WHO), the physical, social and attitudinal factors are important aspects of the environment in which people live and conduct their lives (World Health Organization, 2001). The experience of disability has been described as an outcome of the interaction between a person’s health or functional impairment and environmental factors. It is now recognised that characteristics of the impairment as well as social and physical factors are important to consider in the understanding of disability (Schneidert, Hurst, Miller, & Ustan, 2003).

The International classification of functioning, disability and health (ICF) provides an internationally recognized framework for describing health conditions, health-related states and health outcome measurement (World Health Organization, 2001). Components of the ICF include body functions and structures, activity, participation and contextual components which include environmental and personal factors. When we recently reviewed factors affecting the transition from school to post-school for young adults with intellectual disabilities we found little information on the impact of environmental factors (Foley, Dyke, Girdler, Bourke, & Leonard, 2012). Our review employed the ICF as a guiding framework and demonstrated that the ICF is a useful tool for framing transition research (Study 1 of this thesis).

A large scale longitudinal study investigating influence of environmental factors on participation and quality of life of children and adolescents with cerebral palsy across nine European regions has been undertaken by the SPARCLE group (Colver, 2006; Productivity Commission., 2011). Levels of participation for children with cerebral palsy were considerably lower than that of the general population and particularly so for those with severe motor impairment and more impairments in general. The attitudinal environment, reflected by environmental law, regulation and physical and social environment, also varied considerably across the European Union countries included in the study (Colver et al., 2010). The SPARCLE group employed the Measure of the Quality of the Environment (MQE), which identifies factors that are facilitators or barriers to participation (Levasseur, Desroisers, & Tribble, 2008). It is now recognised that measures of the environment should include not only assistive technology and access to and availability of services but also other factors such as access to benefits, friendships and social integration, and attitudes of others and social inclusion (Yoder & Warren, 2002). The Measure of the Quality of the Environment (MQE) is an instrument which includes domains addressing these additional factors and can be matched to the ICF categories (Fougeyrollas, Noreau, St-Michael, & Boschen, 2008). Additionally, the MQE domains can be matched to the domains of the Assessment of Life Habits (LIFE-H) a measure of social participation used by the SPARCLE group (Colver, 2006; Noreau, Fougeyrollas, & Vincent, 2002).

The contribution of environmental factors to the disability of individuals with Down syndrome has not been explored previously. Once these contextual factors have been identified, there may be scope to modify them and therefore lessen the experience of disability for young people with Down syndrome and for those with similar intellectual impairments (Schneidert et al., 2003). Therefore, the aims of this research were to use a population-based data source to describe the social participation of young adults with Down syndrome from a parental perspective and to explore the relationship between levels of social participation and the physical and social environment. Specifically, the main research question was, what is the relationship between participation in social roles for young people with Down syndrome and the social and physical environment?

## 7.3 Methods

In 2011 parent report questionnaires were administered to families of young people aged between 16 and 32 years in the Western Australian Down syndrome 'Needs Opinions Wishes' (NOW) population-based database (Bourke et al., 2009; Foley et al., 2013). Paper copies of the questionnaires were mailed to families in the Down syndrome NOW database and families were given the option to complete the questionnaire on paper, on the internet or via phone interviews. All families were phoned within a few days of sending out the questionnaires in order to achieve personal contact, provide clear explanation of the study and encourage participation. Prior to mailing questionnaires to participants all families were sent a summary booklet of the findings from the previous wave of questionnaires administered in 2009 (Foley et al., 2014; Foley et al., 2013). (Study 4 of this thesis, refer to Appendix H).

The parent report questionnaires contained two parts; part one described young person characteristics including demographic information, presence of medical conditions, health service use and emotional and behavioural problems, as well as information about everyday functioning in activities of daily living, social relationships and day occupations. Part two contained information about family characteristics including family communication, support, informal assistance needs, availability of time and family quality of life. Detailed description of data collection methods has been previously reported (Bourke et al., 2009; Foley et al., 2013). Ethics approval for this study was obtained through the Ethics Committee of the Women's and Children's Health Services in Western Australia and the Human Research Ethics Committee of Edith Cowan University.

### 7.3.1 Measures

*Participation: Assessment of Life Habits (LIFE-H)*

The Assessment of Life Habits (LIFE-H) is a measure of social participation and includes twelve life domains (nutrition, fitness, personal care, communication, housing, mobility, responsibilities, employment, education, relationships, community life and recreation). It is also possible to calculate daily activities and social roles accomplishment sub scores (Fougeyrollas, 1998). The subscore for social roles was used as the main outcome variable. Domains within the social roles subscore of the LIFE-H described participation as defined by the ICF more specifically than the overall LIFE-H score. For example, engagement in relationships, community life and recreation capture the ICF's description of 'involvement in life situations' rather than one's ability to accomplish activities such as eating meals or sleeping. The latter, describes the activity domain of the ICF (World Health Organization, 2001). The social roles subscore of the LIFE-H does not describe every domain listed in the ICF within the participation component, however, 'as the ICF has only recently been published, no instruments are available, designed and based on this ICF concept (participation)' (Perenboom & Chorus, 2003, p. 577). The LIFE-H was the most closely aligned measure to the participation component of the ICF.

The LIFE-H has been employed in populations of people with spinal cord injury, stroke, traumatic brain injury, children and older adults with cerebral palsy, but not yet with adolescence or young adults with Down syndrome (Desroisers et al., 2007; Noreau et al., 2004; Noreau et al., 2007). The scores can also be presented in accordance with the ICF, by quantifying the scores by percentiles and applying the appropriate qualifying words. For example, minor restrictions (LIFE-H score ≥ 8), moderate (LIFE-H score 4-7) or severe restrictions (LIFE-H score ≤ 3). This provides a universally understood and clinically relevant presentation of the data (Fougeyrollas, Tremblay, Noreau, St-Onge, & Dumont, 2006).

Two specific elements are involved in this measure, 1) level of accomplishment of the daily activity and 2) type of assistance required (no assistance, adaptation, device or human assistance). An item score between 0 (not accomplished) to 9 (accomplished independently, without difficulty) is calculated for each life domain. In order to account for the variable number of items within each domain of life habits and the 'non applicable' items, a scoring system has been proposed (Fougeyrollas, Noreau, & St-Michael, 2001; Noreau et al., 2004). A weighted score was calculated by the summation of raw scores, divided by the number of applicable items (Fougeyrollas et al., 2001; Noreau et al., 2004). A score may be obtained for each item, each life domain (mean of items), or for the two subscales (daily activities and social roles). We did not include the education life domain in the social roles sub-score, as many participants had already left school and thus this life domain was only applicable to less than half of the sample (n=80). Parent reported level of satisfaction was scored within each life domain and was reported on a 5-point likert scale 0 (very dissatisfied) to 4 (very satisfied). The satisfaction score is reported separately and used to evaluate the individual's quality of social participation (Fougeyrollas, 1998).

#### *Environment: Measure of the Quality of the Environment (MQE)*

The MQE was designed to identify environmental factors which were facilitators or barriers to participation and has been used to measure their influence on people with stroke, cerebral palsy and spinal cord injuries (Boschen, Noreau, & Fougeyrollas, 1998; Boucher, Dumas, Maltais, & Richards, 2010; Fougeyrollas, Noreau, St-Michael, & Boschen, 1999; Levasseur, Desroisers, & Noreau, 2004; Levasseur et al., 2008; Rochette, Desroisers, & Noreau, 2001; Vik, Nygard, & Lilja, 2007). The items correspond to the environmental factors described within the ICF (Levasseur et al., 2004) and cover six domains: social support and attitudes (14), income, labour and income security (15), government and public services (27), equal opportunities and political orientations (10), physical environment and accessibility (38) and technology (5). Generally the last two domains refer to the physical environment (40 items) while the remainder refer to the social environment (69 items) (Levasseur et al., 2008).

Overall, the domains within the MQE align very well to the codes in the environment component of the ICF and similar language is used, such as referring to the environmental factors as facilitators or barriers (World Health Organization, 2001). The subscale describing the social environment also accurately aligns with the ICF. The physical environment describes public infrastructure including public transport, and communication services which suits the ICF description of the physical environment. However, other items within the physical environment subscale describe the influence of cultural services, religious organizations and athletic and recreational services which could be argued to not fit with the ICFs definition of the physical environment. This presents a limitation in interpretation of the overall influence the physical environment as aligned with the ICF. To overcome this, these results should be interpreted with specification of the MQEs definition of the physical environment (Levasseur et al., 2008).

### *Emotional and behavioural problems: Developmental Behaviour Checklist – Adult Version (DBC-A)*

The DBC-A is 107-item checklist which measures emotional and behavioural problems and was developed specifically for use with adults with intellectual and/or developmental disability. Each behavioural response is scored as 0 (not true as far as you know), 1 (somewhat or sometimes true) or 2 (very true or often true). The DBC-A has been found to have acceptable test-retest and inter-rater reliability and convergent ability has been demonstrated with two measures of behavioural disturbances of adults with intellectual disability (Mohr, Tonge, & Einfeld, 2005).

*Functioning in activities of daily living: Index of Social Competence (ISC)*

The Index of Social Competence (ISC) (McConkey & Walsh, 1982) was used to measure domains of communication, self-care and community skills. This measure discriminates well between different levels of ability (McEvoy & Dagnan, 1993).

### 7.3.2 Data analysis

Descriptive statistics including means, standard deviations and ranges, were used to describe the participation (LIFE-H) and environment (MQE) data. Univariate relationships between independent variables (see Table 20 for a list of independent variables) and the outcome, subscores of the LIFE-H, were examined using analysis of variance and chi-squared tests. Logistic regressions with binary outcomes were used in the final models allowing for adjustment for confounding variables. The outcome was binary as we combined those who reported the environment as having 'no influence' or being a 'barrier' together and compared them to those who reported the environment as a facilitator. It is useful to identify those environmental factors which were facilitators to then provide targets for intervention to make a positive impact on participation for young people with Down syndrome. Confounding variables were identified through the use of the ICF. Examining the relationship between participation and environment required accounting for confounding variables which represented the other domains of the ICF. Therefore the confounding variables which were adjusted for in the final model were age and gender (personal factors), emotional and behavioural problems (impairment of body functions and structures) and functioning in activities of daily living (activity) (World Health Organization, 2001). Unadjusted and adjusted models were reported separately. STATA 11 was used for all analyses (Statacorp, 2003).

## 7.4 Results

Families of 197/223 (88.3%) young people returned the 2011 Down syndrome 'NOW' questionnaire. This study will focus on the 166/197 (84.3%) families who returned the parent report questionnaires with sufficient data on the participation and environment measures. The majority (136/166, 81.9%) of the young adults lived with their parents in their family home, others lived with other family or friends (11/166, 6.6%), five lived in a group home (3.0%) and four young adults lived alone (2.4%).

### 7.4.1 Participation

Eight (4.9%) young adults were reported by their parents as experiencing severe restrictions in engagement in daily activities, 126 (75.9%) moderate and 27 (16.3%) minor restrictions. Participation in social roles was reported as severely restricted in 18 young adults (10.8%), moderate for 117 (70.5%) and a minor restriction for six (3.6%)(Table 18). The domain reported with the lowest participation score was the responsibilities domain (mean 3.75 SD 2.27), which relates to recognizing the value of money, making purchases and planning budgets. Participation in education (mean 4.52, SD 2.67), community life (mean 4.72 SD 2.54) and recreation (mean 4.81, SD 2.38) also scored low participation scores (Table 2). These are all domains normally included in the social roles subscore but for this study we did not include the education domain. Participation in housing and fitness domains scored the highest of the domains within the LIFE-H (mean 7.51 SD 1.69, mean 7.41 SD 1.66, respectively). The housing domain involved taking part in housekeeping tasks, entering and exiting the home and using household equipment (furniture, lighting and outdoor equipment). The fitness domain described participating in physical activities and relaxation activities as well as sleep and getting in and out of bed.

### 7.4.2 Environment

Parent perception of whether the environmental factor within the MQE was a major obstacle or major facilitator was scored on a 7-point Likert scale. Reponses to each item are presented in Table 19. Two continuous scores were calculated by summing the items and dividing into percentiles, one describing the physical environment and one describing the social environment. Approximately one third of the parents who provided data on the MQE reported the social environment as mainly a facilitator to

Table 18: Mean LIFE-H scores by life domain categories and sub-scores (daily activity and social roles) and number of participants reported as experiencing severe, moderate or minor restrictions in participation

| | | | | Participation Restrictions | | | |
|---|---|---|---|---|---|---|---|
| Continuous variables | Freq | Mean LIFE-H score (SD) | Range LIFE-H score | Severe n (%) (score ≤ 3) | Moderate n (%) (score 4-7) | Minor n (%) (Score ≥ 8) | Missing/NA n (%) |
| Social Participation (LIFE-H) | | | | | | | |
| *Daily activities categories* | | | | | | | |
| Nutrition | 166 | 5.91 (2.14) | 0.25, 9 | 18 (10.8) | 112 (67.5) | 36 (21.7) | 0 |
| Fitness | 164 | 7.41 (1.66) | 1.25, 9 | 2 (1.2) | 81 (48.8) | 81 (48.8) | 2 (1.2) |
| Personal care | 165 | 6.33 (2.29) | 0, 9 | 20(12.0) | 99 (59.6) | 46 (27.7) | 1 (0.6) |
| Communication | 164 | 5.60 (2.48) | 0, 9 | 29 (17.5) | 99 (59.6) | 36 (21.7) | 2 (1.2) |
| Housing | 162 | 7.51 (1.69) | 0.5, 9 | 4 (2.4) | 80 (48.2) | 78 (47.0) | 4 (2.4) |
| Mobility | 163 | 5.90 (2.11) | 0.2, 9 | 15 (9.0) | 113 (68.1) | 35 (21.1) | 3 (1.8) |
| Daily activities subscore | 161 | 6.45 (1.65) | 0.81, 8.86 | 8 (4.9) | 126 (75.9) | 27 (16.3) | 5 (3.0) |
| *Social roles categories* | | | | | | | |
| Responsibility | 161 | 3.75 (2.27) | 0, 9 | 68 (41.0) | 87 (52.4) | 6 (3.6) | 5 (3.0) |
| Employment | 146 | 5.47 (2.83) | 0, 9 | 34 (20.5) | 76 (45.8) | 36 (21.7) | 20 (12.0) |
| Education[a] | 80 | 4.52 (2.67) | 0, 9 | 37 (22.2) | 27 (16.3) | 16 (9.6) | 86 (51.8) |
| Relationships | 159 | 6.66 (2.34) | 0, 9 | 17 (10.2) | 75 (45.2) | 67 (40.4) | 7 (4.2) |
| Community life | 163 | 4.72 (2.54) | 0, 9 | 52 (31.3) | 87 (52.4) | 24 (14.5) | 3 (1.8) |
| Recreation | 159 | 4.81 (2.38) | 0, 9 | 44 (26.5) | 93 (56.0) | 22 (13.3) | 7 (4.2) |
| Social roles subscore | 141 | 5.17 (1.84) | 0.22, 8.93 | 18 (10.8) | 117 (70.5) | 6 (3.6) | 25 (15.1) |

[a] Education not included in social roles subscore

*Note.* LIFE-H, Assessment of Life Habits, Freq, frequency participation (n=45, 27.1%) and just over one third reported the physical environment as mainly a facilitator (n=59, 35.5%). Just over one third reported the social and physical environment as having no influence (n=63, 38.0%, n=64, 38.6%, respectively) and a very small proportion reported the overall social and physical environment as a barrier to participation (n=2, 1.2%, n=7, 4.2%). Data for the remaining families concerning the influence of the overall social and physical environment were missing, reported as ‘I don’t know’ or ‘Does not apply’ (Table 19).

Within the social environment sub-scale the most commonly reported facilitators to participation were the family situation (n=125, 75.3%), attitudes of families and close friends (n=120, 72.3%), colleagues (n=118, 71.2%) and superiors (n=121, 72.3%). The most commonly reported barriers to participation in the social environment were related to support from friends (n=44, 26.5%) and neighbours (n=34, 20.5%), current availability of jobs (n=40, 24.1%) and job criteria (n=38, 22.9%) and attitudes of strangers (n=26, 15.7%).

### 7.4.3 Relationship between participation and physical and social environment

The two subscores of the participation measure, daily activities and social roles, and their relationship with independent variables including demographics, behavior, and environmental factors are presented in Table 20. There was no difference in engagement in daily activities or social roles by gender, family income or place of residence. Attitudes of others were associated with engagement in daily activities, with those parents who considered attitudes of others to be a facilitator or have no influence reporting a higher participation score (mean 6.33 SD 1.44, mean 6.71 SD 1.50, respectively) than those who considered attitudes of others to be a barrier (mean 4.16 SD 2.08). Similarly, those who considered social networks to be a barrier were more likely to report lower engagement in daily activities (mean 5.46 SD 2.01) than those who considered social networks to be a facilitator or have no influence (mean 6.13 SD 1.84, mean 6.69 SD 1.35, respectively). Those who considered the influence of commercial services such as grocery stores, restaurants and shopping centres as a facilitator to participation reported higher participation in social roles (mean 5.53 SD 1.59) than those who considered them as barriers (mean 4.73 SD 1.84). This relationship was weaker for engagement in daily activities (Table 20).

The unadjusted logistic regression model showed that when the physical and/or social environment was considered as a facilitator, compared to being no influence or a barrier, then participation in social roles increased (coef 0.89, 95%CI 0.28, 1.52, coef 0.83, 95%CI 0.17, 1.49, respectively)(Table 21). Confounding variables of age, gender, emotional and behavioural problems as measured by the DBC and functioning in activities of daily living (ADL) as measured by ISC were included in the adjusted regression model (Table 21). The addition of these confounding variables reduced the strength of the relationship between the facilitating effect of the social environment and increased participation in social roles (coef 0.20, 95%CI -0.47, 0.87). This was similar for the physical environment, however the effect persisted more so than for the social environment (coef 0.60, 95% CI -0.40, 1.24). We considered stratifying the regression analysis by level of functioning in order to investigate if there were differences in the participation outcome. Other studies have identified that functioning in activities of daily living can be associated with different domains of participation (Foley et al., 2013; Rihtman et al., 2010; Wuang & Su, 2011). However when we explored this interaction in this study within the regression between functioning in ADL and environment no association was found.

## 7.5 Discussion

Young people with Down syndrome were reported to have more difficulty participating in social roles (e.g. relationships, community life, recreation etc.) than they did participating in daily activities (e.g. personal care, communication, housing etc.). The majority of young people with Down syndrome experience moderate participation restrictions in daily activities and social roles. We found that young adults' participation in social roles is influenced by the physical environment (including public infrastructure and community organization services) more than by the social environment, however both were weak associations. Of concern, is the fact that the most commonly reported barriers to participation were attitudes of strangers, support from friends, availability of jobs and public transport. The most commonly cited facilitators to young person participation were family and close friends, young person's current workplace (if they were employed), and attitudes of superiors and colleagues of the young person.

The main strength of this study is that it is framed within the internationally recognized disability framework, the ICF. Examining the complex situation of the environment's influence on social participation while accounting for personal (age and gender) and impairment factors (emotional and behavioural problems) can be clarified through the use of the ICF. Another strength is the quantitative description through a standardized measure of social participation and the influence of the environment of young people with Down syndrome through the use of cases ascertained from a population-based database (Yoder & Warren, 2002). The high response fraction enables further generalization of findings to the wider population of young people with Down syndrome across Australia and internationally and perhaps intellectual disability from other causes. However, there were some missing data in the environment (MQE) and participation (LIFE-H) measures. The cross-sectional design of this study meant we were unable to define the causal direction of the relationship between participation and environment. Another consideration is the fact that the young people may not consider barriers to participation in the same way as their parents. Also, as mentioned in the 'Methods' section, caution should be taken in interpreting these results with the definition of physical environment from the ICF, rather the physical environment was defined as per the MQE (Levasseur et al., 2008). A significant strength is that there were barriers to participation identified from the parents' perspective (for example attitudes of others, availability of jobs and public transport) that have the potential to be modified through policy and intervention strategies.

The finding of a relationship between the physical environment as a facilitator and increased participation in social roles was interesting. We had hypothesized that the social environment would have had a stronger influence on participation in social roles. Elements of the physical environment included public transport, cultural and religious services and recreational and community organization. Previous research into factors that were barriers to social inclusion from the perspectives of young people with an intellectual disability highlighted four main elements, one of which related to the physical environment. This element was the location of their house, and the availability of transport to and from the house (May, 2001). In Ireland, barriers to leisure participation for adolescents with intellectual disability were ‘access to’ and ‘location of’ leisure facilities from both young person and parent perspectives (Buttimer & Tierney, 2005). Inclusion of the variables representing the body functions and structures and activity domains of the ICF reduced the strength of the relationship, further highlighting the complex interaction between the social-psychological and biological factors that contribute to overall functioning. Emerging evidence suggests that the physical environment has the potential to have a large impact on the participation for young adults with intellectual disability and provides a new avenue for intervention.

From the parents’ perspective, our study shows that the attitudes of others act as a barrier to participation for young people with Down syndrome. Previous research involving people with an intellectual disability has explored social distance and described the relative willingness of an individual to take part in relationships of varying degrees of intimacy with a person who has a stigmatized identity (Nuehring & Sitlington, 2003). The authors of this research reported that older people and people with lower education levels endorsed a higher level of social distance

Table 19: Parent reported influences of environmental factors on the accomplishment of daily activities (n=166)

| Environmental factors | Barrier (%) | No influence (%) | Facilitator (%) | Does not apply (%) | Missing/ I don't know (%) |
|---|---|---|---|---|---|
| Social networks | | | | | |
| Family situation | 13 (7.8) | 6 (3.6) | 125 (75.3) | 10 (6.0) | 12 (7.2) |
| Support from family | 16 (9.6) | 12 (7.2) | 115 (69.3) | 13 (7.8) | 10 (6.0) |
| Support from friends | 44 (26.5) | 21 (12.7) | 70 (42.2) | 19 (11.4) | 12 (7.2) |
| Support from neighbours | 34 (20.5) | 1 (0.6) | 45 (27.1) | 26 (15.7) | 60 (36.1) |
| Support from colleagues | 13 (7.8) | 15 (9.0) | 107 (64.5) | 18 (10.8) | 13 (7.8) |
| Attitudes of people around | | | | | |
| Families and close friends | 9 (5.4) | 9 (5.4) | 120 (72.3) | 16 (9.6) | 12 (7.2) |
| Attitudes of friends | 15 (9.0) | 26 (15.7) | 95 (57.2) | 13 (7.8) | 17 (10.2) |
| Attitudes of colleagues | 7 (4.2) | 13 (7.8) | 118 (71.2) | 11 (6.6) | 17 (10.2) |
| Attitudes of superiors | 8 (4.8) | 12 (7.2) | 121 (72.3) | 8 (4.8) | 17 (10.2) |
| Attitudes of neighours | 12 (6.1) | 52 (31.3) | 65 (39.2) | 19 (11.4) | 21 (12.7) |
| Attitudes of service providers | 15 (7.2) | 20 (10.1) | 107 (64.5) | 5 (3.0) | 22 (13.3) |
| Attitudes of strangers | 26 (15.7) | 43 (12.0) | 69 (41.6) | 8 (4.8) | 23 (13.9) |
| Attitudes of people when there in a group (class, crowd) | 22 (13.3) | 25 (12.6) | 93 (56.0) | 5 (3.0) | 24 (14.5) |
| Religious beliefs of people in your community | 7 (4.2) | 60 (15.1) | 53 (31.9) | 22 (13.3) | 24 (14.5) |
| Employment services | | | | | |
| Counseling and employment seeking services | 13 (7.8) | 33 (19.8) | 43 (25.9) | 55 (33.1) | 22 (13,3) |
| Current availability of jobs in your community | 40 (24.1) | 26 (15.7) | 15 (9.0) | 55 (33.1) | 30 (18.1) |
| Job criteria/tests | 38 (22.9) | 23 (13.9) | 13 (7.8) | 57 (34.3) | 35 (21.1) |
| Currently employed only | | | | | |
| Their workplace | 6 (3.6) | 7 (4.2) | 77 (46.4) | 76 (45.8) | |
| Requirements of work tasks | 7 (4.2) | 4 (2.4) | 81 (48.8) | 74 (44.6) | |
| Their work hours | 6 (3.6) | 6 (3.6) | 76 (45.8) | 77 (46.4) | |
| Union structures | 3 (1.8) | 28 (16.9) | 15 (9.0) | 120 (72.3) | |
| Employee services | 2 (1.2) | 17 (10.2) | 40 (24.1) | 107 (64.5) | |
| Financial Resources | | | | | |
| Personal income | 23 (13.8) | 24 (14.5) | 93 (56.0) | 7 (4.2) | 22 (13.3) |
| Public disability programs (e.g. Disability pensions) | 16 (9.6) | 16 (9.6) | 108 (65.1) | 2 (1.2) | 22 (13.3) |

| Environmental factors | Barrier (%) | No influence (%) | Facilitator (%) | Does not apply (%) | Missing/ I don't know (%) |
|---|---|---|---|---|---|
| *Social environment Subscale* | 2 (1.2) | 63 (38.0) | 45 (27.1) | 56 (33.7) | |
| Private health insurance programs | 16 (9.6) | 35 (21.1) | 68 (41.0) | 28 (16.9) | 22 (13.3) |
| Commercial services | | | | | |
| Availability of business (e.g. shopping centres) | 12 (7.2) | 29 (17.5) | 88 (53.0) | 18 (10.8) | 22 (13.3) |
| Services offered by business | 11 (6.6) | 43 (25.9) | 66 (39.8) | 22 (13.3) | 24 (14.5) |
| Other support services | | | | | |
| Support workers other than family | 7 (4.2) | 15 (9.0) | 105 (63.3) | 23 (13.9) | 16 (9.6) |
| Home care services | 7 (4.2) | 34 (20.5) | 40 (24.1) | 70 (42.2) | 15 (9.0) |
| Health services (e.g. hospital, medical clinic) | 9 (5.4) | 25 (15.1) | 100 (60.2) | 15 (9.0) | 17 (10.2) |
| Physical and social rehabilitation services in community | 7 (4.2) | 39 (23.5) | 38 (22.9) | 62 (37.3) | 20 (12.0) |
| Vocational services in community | 11 (6.6) | 40 (24.1) | 30 (18.1) | 60 (36.1) | 25 (15.1) |
| Social integration support services (e.g. social work, residential resources) | 14 (8.4) | 34 (20.5) | 42 (25.3) | 51 (30.7) | 25 (15.1) |
| Educational services | | | | | |
| Educational service in community (e.g. TAFE) | 2 (1.2) | 5 (3.0) | 31 (18.7) | 7 (4.2) | 121 (72.9) |
| Access to student loans | 1 (0.6) | 36 (21.7) | 5 (3.0) | 1 (0.6) | 123 (74.1) |
| Other educational services | 1 (0.6) | 15 (9.0) | 7 (4.2) | 21 (12.7) | 122 (73.5) |
| *Physical environment subscale* | 7 (4.2) | 64 (38.6) | 59 (35.5) | 36 (21.7) | |
| Public infrastructure | | | | | |
| Public transport | 36 (21.7) | 19 (11.4) | 57 (34.3) | 41 (24.7) | 13 (7.8) |
| Specially routed buses/trains for people with disabilities | 29 (17.5) | 28 (16.9) | 29 (17.5) | 67 (40.4) | 13 (7.8) |
| Long distance transport (bus, plane) | 19 (11.4) | 45 (27.1) | 33 (19.9) | 51 (30.7) | 21 (12.7) |
| Communication services (telephone, internet) | 13 (7.8) | 33 (19.9) | 67 (40.4) | 37 (22.2) | 16 (9.6) |

| Environmental factors | Barrier (%) | No influence (%) | Facilitator (%) | Does not apply (%) | Missing/ I don't know (%) |
|---|---|---|---|---|---|
| Radio media services | 8 (4.8) | 57 (34.3) | 37 (22.2) | 47 (28.3) | 17 (10.2) |
| Television media services | 8 (4.8) | 0 | 98 (59.0) | 37 (22.2) | 23 (13.9) |
| Community organization services | | | | | |
| Cultural services | 6 (3.6) | 18 (10.8) | 104 (62.7) | 22 (13.3) | 16 (9.6) |
| Religious organisations | 6 (3.6) | 45 (27.1) | 54 (32.5) | 45 (27.1) | 16 (9.6) |
| Athletic and recreational organization services | 11 (6.6) | 19 (11.4) | 105 (63.3) | 17 (10.2) | 14 (8.4) |
| Community organizations (craft/social groups) | 11 (6.6) | 33 (19.9) | 68 (41.0) | 37 (22.2) | 17 (10.2) |

*Note.* TAFE, Technical and Further Education

Table 20: Univariate relationship between social participation and independent variables (n=166)

| | Social Participation (LIFE-H) (0-9) | | | |
|---|---|---|---|---|
| | Daily activities sub-score | | Social roles sub-score | |
| Independent variables | Frequency | Mean (SD) | Frequency | Mean (SD) |
| Personal factors | | | | |
| Gender | | | | |
| Male | 88 (53.0) | 6.37 (1.78) | 77 (46.4) | 5.02 (1.8) |
| Female | 73 (44.0) | 6.54 (1.49) | 64 (38.6) | 5.36 (1.88) |
| Missing | 5 (3.0) | - | 25 (15.1) | - |
| Age group | | | | |
| 16≤20 year olds | 36 (21.7) | 6.01 (1.79) | 29 (17.5) | 4.79 (1.61) |
| 21≤25 year olds | 52 (31.3) | 6.38 (1.72) | 46 (27.7) | 5.32 (2.01) |
| 26≤32 year olds | 73 (44.0) | 6.71 (1.49) | 66 (39.8) | 5.24 (1.80) |
| Missing | 5 (3.0) | - | 25 (15.1) | - |
| Environmental factors | | | | |
| Annual family income | | | | |
| $78000 and above | 72 (43.4) | 6.58 (1.55) | 36 (21.7) | 5.22 (1.91) |
| Between $41600 and $77999 | 33 (19.9) | 6.18 (1.61) | 27 (16.3) | 5.04 (1.41) |
| Less than $41599 | 42(25.3) | 6.33 (1.81) | 65 (39.2) | 5.07 (2.03) |
| Missing | 19 (11.4) | - | 38 (22.9) | - |
| Place of residence | | | | |
| Family home | 136 (81.9) | 6.32 (1.67) | 120 (72.3) | 5.04 (1.81) |
| Group home/hostel | 5 (3.0) | 6.40 (1.46) | 4 (2.4) | 5.35 (2.16) |
| Living alone | 4 (2.4) | 7.02 (0.80) | 3 (1.8) | 5.74 (1.71) |
| Living with family/friends | 11 (6.6) | 7.48 (1.53) | 9 (5.4) | 6.14 (1.99) |
| Missing | 10 (6.0) | - | 30 (18.1) | - |
| Living Region | | | | |
| Major city (Perth) | 117 (70.5) | 6.42 (1.65) | 102 (61.4) | 5.09 (1.79) |
| Regional/remote | 44 (26.5) | 6.53 (1.66) | 39 (23.5) | 5.38 (1.95) |
| Missing | 5 (3.0) | - | 25 (15.1) | - |
| MQE Subscales | | | | |
| Social networks | | | | |
| Barrier | 12 (7.2) | 5.46 (2.01) | 10 (6.0) | 4.36 (1.49) |
| No influence | 42 (25.3) | 6.13 (1.84) | 34 (20.5) | 4.90 (1.79) |

| | Social Participation (LIFE-H) (0-9) | | | |
|---|---|---|---|---|
| | Daily activities sub-score | | Social roles sub-score | |
| Independent variables | Frequency | Mean (SD) | Frequency | Mean (SD) |
| Facilitator | 94 (56.6) | 6.69 (1.35) | 87 (52.4) | 5.37 (1.76) |
| Missing | 18 (10.8) | - | 35 (21.1) | - |
| Attitudes of others | | | | |
| Barrier | 5 (3.0) | 4.16 (2.08) | 5 (3.0) | 4.01 (1.42) |
| No influence | 52 (31.3) | 6.33 (1.44) | 43 (25.9) | 5.22 (1.59) |
| Facilitator | 89 (53.6) | 6.71 (1.50) | 81 (48.8) | 5.34 (1.79) |
| Missing | 20 (12.0) | - | 37 (22.3) | - |
| Employment services | | | | |
| Barrier | 19 (11.4) | 6.12 ((1.93) | 16 (9.6) | 4.66 (1.75) |
| No influence | 42 (25.3) | 6.53 (1.51) | 38 (22.9) | 5.22 (1.82) |
| Facilitator | 59 (35.5) | 6.80 (1.31) | 57 (34.3) | 5.67 (1.59) |
| Missing | 46 (27.7) | - | 55 (33.1) | - |
| Financial resources | | | | |
| Barrier | 13 (7.8) | 5.09 (2.33) | 9 (5.4) | 3.99 (1.56) |
| No influence | 37 (22.3) | 6.48 (1.39) | 31 (18.7) | 5.41 (1.61) |
| Facilitator | 92 (55.4) | 6.55 (1.55) | 85 (51.2) | 5.25 (1.85) |
| Missing | 24 (14.5) | - | 41 (24.7) | - |
| Commercial services | | | | |
| Barrier | 11 (6.6) | 5.55 (2.21) | 8 (4.8) | 4.73 (1.84) |
| No influence | 37 (22.3) | 6.34 (1.50) | 34 (20.5) | 4.69 (1.69) |
| Facilitator | 76 (45.8) | 6.68 (1.39) | 70 (42.2) | 5.53 (1.59) |
| Missing | 42 (25.3) | - | 54 (32.5) | - |
| Other support services | | | | |
| Barrier | 5 (3.0) | 4.70 (2.79) | 5 (3.0) | 4.08 (1.68) |
| No influence | 55 (33.1) | 6.19 (1.69) | 48 (28.9) | 5.05 (1.87) |
| Facilitator | 78 (47.0) | 6.58 (1.59) | 69 (41.6) | 5.31 (1.77) |
| Missing | 28 (16.9) | - | 44 (26.5) | - |
| Education services | | | | |
| Barrier | 1 (0.6) | 7.78 (0) | 1 (0.6) | 6.65 (0.0) |
| No influence | 18 (10.8) | 6.34 (1.47) | 15 (9.0) | 5.26 (1.87) |
| Facilitator | 25 (15.1) | 6.44 (1.91) | 21 (12.7) | 4.94 (1.82) |
| Missing | 122 (73.5) | - | 129 (77.7) | - |
| Public infrastructure | | | | |

| | Social Participation (LIFE-H) (0-9) | | | |
|---|---|---|---|---|
| | Daily activities sub-score | | Social roles sub-score | |
| Independent variables | Frequency | Mean (SD) | Frequency | Mean (SD) |
| Barrier | 17 (10.2) | 5.67 (2.00) | 14 (8.4) | 4.85 (1.70) |
| No influence | 49 (29.5) | 6.55 (1.37) | 45 (27.1) | 5.12 (1.83) |
| Facilitator | 61 (36.7) | 6.75 (1.69) | 55 (33.1) | 5.60 (1.66) |
| Missing | 39 (23.5) | - | 52 (31.3) | - |
| Community organization services | | | | |
| Barrier | 4 (2.4) | 4.34 (1.97) | 3 (1.8) | 3.55 (1.72) |
| No influence | 38 (22.9) | 6.34 (1.44) | 35 (21.1) | 5.01 (1.87) |
| Facilitator | 98 (59.0) | 6.62 (1.56) | 85 (51.2) | 5.42 (1.61) |
| Missing | 26 (15.7) | - | 43 (25.9) | - |
| Physical environment subscore | | | | |
| Barrier | 6 (3.6) | 4.33 (1.54) | 5 (3.0) | 3.34 (1.26) |
| No influence | 57 (34.3) | 6.42 (1.45) | 51 (30.7) | 5.06 ( 1.77) |
| Facilitator | 62 (37.3) | 6.90 (1.52) | 56 (33.7) | 5.80 (1.49) |
| Missing | 41 (24.7) | - | 54 (32.5) | - |
| Social environment subscore | | | | |
| Barrier | 2 (1.2) | 2.76 (1.13) | 2 (1.2) | 2.77 (1.36) |
| No influence | 44 (26.5) | 6.33 (1.67) | 37 (22.3) | 4.88 (1.68) |
| Facilitator | 61 (36.7) | 6.76 (1.21) | 59 (35.5) | 5.60 (1.54) |
| Missing | 59 (35.5) | - | 68 (41.0) | - |
| Day Occupation | | | | |
| Still at school | 10 (6.0) | 5.68 (2.14) | 7 (4.2) | 4.37 (2.00) |
| Open employment | 35 (21.1) | 7.15 (1.13) | 33 (19.9) | 5.99 (1.73) |
| Training | 20 (12.0) | 6.90 (1.25) | 18 (10.8) | 5.56 (1.28) |
| Sheltered employment | 61 (36.7) | 6.60 (1.47) | 59 (35.5) | 5.32 (1.57) |
| Day recreation programs | 33 (19.9) | 5.30 (1.90) | 24 (14.5) | 3.65 (2.05) |
| Not working | 2 (1.2) | 7.39 (0.8) | 0 | - |
| Missing | 5 (3.0) | - | 25 (15.1) | - |

*Note.* LIFE-H, Assessment of Life Habits, SD, standard deviation

Table 21: Binary logistic regressions of the relationship between the physical and social environment and participation in social roles

| | | Social roles subscale of LIFE-H | | | | | |
|---|---|---|---|---|---|---|---|
| | | Unadjusted model[a] | | | Adjusted model (n=93) | | |
| | Freq | Coeff[b] | 95% CI | p-value | Coeff[b] | 95% CI | p-value |
| Physical environment subscore | | | | | | | |
| Barrier/No influence | | Reference | | | Reference | | |
| Facilitator | 112 | 0.89 | 0.28, 1.52 | 0.005 | 0.60 | -0.40, 1.24 | 0.06 |
| Social environment subscore | | | | | | | |
| Barrier/No influence | | Reference | | | Reference | | |
| Facilitator | 98 | 0.83 | 0.17, 1.49 | 0.015 | 0.20 | -0.47, 0.87 | 0.59 |

*Note.* Adjusted model includes confounding variables age, gender, behaviour, functioning in ADL

*Note.* LIFE-H, Assessment of Life Habits

[a] The unadjusted models are two separate models, physical environment (n=112) and social environment (n=98)

[b] Per point increase on the outcome measure, Social Roles subscale of the LIFE-H

between themselves and people with an intellectual disability (Nuehring & Sitlington, 2003). Research has highlighted that public knowledge of intellectual disability and causal beliefs are particularly under-researched areas and that one of the main reasons for lay people's reluctance to interact with people with intellectual disability is due to discomfort and anxiety (Scior, 2011). Clearly, public campaigns which promote education and understanding around people with intellectual disability could play a role in limiting social distance and in turn facilitate participation in social roles for people with Down syndrome.

Workplace characteristics including attitudes of superiors and colleagues and the work environment in general were cited by parents as facilitators to participation for those young people who were employed. A questionnaire study involving 643 Australian employers who had employed a person with a disability found that the person with a disability was reported as better than the 'average' employee on reliability variables (attendance and sick leave) and maintenance variables (recruitment, safety, insurance costs) (Graffam, Smith, Shinkfield, & Polzin, 2002). Also, a Canadian study which surveyed the public on views on employment of people with intellectual disabilities found that the people surveyed believed that employing a person with a disability in a workplace would not have a negative effect on the workplace. However, the respondents did highlight lack of employment training programs for people with intellectual disability as a major obstacle to gaining their employment (Burge, Ouellette-Kuntz, & Lysaght, 2007). People with intellectual disability who participated in focus groups and were asked about their perspective on barriers to social inclusion did not cite being employed as a way to improve their inclusion (Abbott & McConkey, 2006). However, those who were employed, often mention social inclusion as a valued outcome of participating in employment (Simons, 1998). While young people with Down syndrome have been reported to find it difficult to find appropriate and suitable jobs (Banks, 2010; Kober

& Eggleton, 2005), it is encouraging that once they were in the workplace, their environment was supportive.

This study focused on the environmental factors that families reported as facilitators to participation in order to identify avenues for intervention. However, factors reported as barriers to participation are important to consider. Overall, there were very small proportions of families who reported the social or physical environment as a barrier, yet just over one third of families reported that the social and physical environment had ‘no influence’ on their son’s/daughter’s participation. Service providers who are aiming to facilitate increased participation for young people with intellectual disabilities should consider adjusting these existing social and physical environmental factors, which act as no influence, to have a positive influence on participation.

There is a developing body of knowledge which reports the impact which negative community attitudes have on social inclusion for young people with intellectual disability (May, 2001). Reports of increased rates of violence against people with disabilities including intellectual disability are concerning (Hughes et al., 2012). In the United States it has been reported that those people with an intellectual disability had a higher risk of violent victimization than persons with any other type of disability and those with intellectual disability experience a higher frequency of sexual assault, robbery and aggravated assault than those with a sensory disability (Rand & Harrell, 2009). A review involving studies from United States, Australia, England and Spain found higher prevalence of physical and sexual abuse maltreatment towards people with intellectual disability compared to those without intellectual disability (Horner-Johnson & Drum, 2006). There is an urgent need to address the lack of population-level data which clearly defines this issue, to then effectively guide resource allocation and service delivery (Horner-Johnson & Drum, 2006; Soylu, Alpaslan, Ayaz, Esenyel, & Oruc, 2013).

## 7.6 Conclusion

Through the use of the internationally renowned framework, ICF, this study has highlighted that young people with Down syndrome experience participation restrictions in involvement in social roles. Parents reported that elements of the environment negatively influence participation including negative attitudes of strangers, and lack of support from friends, availability of jobs and public transport. This study has highlighted the important influence of the physical environment on social participation. This is an influence which may have been previously overlooked and has great potential to be modifiable.

# Chapter 8: Overall discussion and conclusion

The aim of this thesis was to examine the experience of transition from school to post-school for young adults with Down syndrome and investigate factors which are positively and adversely associated with different outcomes in adulthood. This research is unique as families were ascertained from a population-based database and data were collected overtime which provided invaluable longitudinal data. The research was guided by the internationally renowned framework, the ICF, which was recommended by the World Health Organization for research in the field of disability. Six studies were undertaken within this thesis in order to understand how the different domains of the ICF are associated with outcomes in adulthood for people with Down syndrome. Initially, a comprehensive literature review of research relating to transition and young people with intellectual disability was undertaken. Following this, a study involving focus groups with children and young people with a range of disabilities was undertaken to examine their experiences of wellbeing. This study and the initial literature review demonstrated the usefulness of the ICF in framing research for young people with disabilities when investigating multi-faceted and fluid concepts such as wellbeing and participation. These initial studies confirmed that the ICF was the most appropriate framework to guide this thesis and also highlighted the importance that young people with disabilities place on participation. Subsequent studies (Study 3 to 5) investigated the relationship between different components of the ICF and participation including post-school day occupations. The final study, Study 6, investigated the relationship between social participation and the influence of the environment. This chapter concludes the findings from each study of this thesis within the ICF framework and discusses limitations within this research, recommendations for service delivery, knowledge translation and future research.

## 8.1 Conclusions

### 8.1.1 Body functions and structures

The physiological functions of body systems and the anatomical parts of the body are described within the Body Functions and Structures component of the ICF. Elements of this thesis which were related to this domain include examination of the association of medical impairments, health conditions and behavioural problems with participation. In Study Three, the relationship between functioning in ADL and participation in post-school occupations was examined and how presence of health impairment may influence these associations. Interestingly, the presence of health impairments, as measured by annual visits to the General Practitioner had little influence on this relationship. However, there were some limitations to the impairment variable which were discussed in Study Three (Foley et al., 2013).

The impairment variable was measured by counts of annual General Practitioner visits, episodes of illnesses and hospital visits, rather than presence of specific impairments. The hospital visits variable was problematic as many young people were visiting the hospital for preventative or elective surgeries such as removing tonsils, removing wisdom teeth or circumcision. Therefore, this variable was not providing information on impairment. A recent publication from the data within the Down syndrome NOW database found that young adults with Down syndrome commonly experienced problems relating to cardiac (affecting 25%), respiratory (affecting 36%), eye and vision (affecting 73%), ear and hearing (affecting 45%) and musculoskeletal systems (affecting 61%) (Pikora, Bourke, Bathgate, Foley, Lennox, et al., 2014). Body weight issues (affecting 57%), skin problems (affecting 56%) and mental health conditions (affecting 32%) were also reported (Pikora et al., 2014). These data were compared with previously collected population based data on children with Down syndrome (Fitzgerald et al., 2013; Leonard, Glasson, Bebbington, Hammond, Croft et al., 2013). It was concluded that adolescents with Down syndrome experienced fewer acute problems, especially respiratory, but more lifestyle related problems (e.g. mental health, obesity and musculoskeletal problems). Exploration of how lifestyle problems may influence participation in post-school day occupations for people with Down syndrome should be a focus of future research.

In populations of people with mental health problems, employment has been shown to positively impact more areas of life than almost any other intervention and has been strongly linked with better quality of life and wellbeing (Marwaha, Johnson, Bebbington, Angermeyer, Brugha et al., 2008; Boardman, Grove, Perkins, & Shephard, 2003; Marwaha, Gilbert, & Flanagan, 2014). Investigation of the relationship between the emerging lifestyle problems present in the lives of young people with Down syndrome, such as mental health problems, and participation in employment is required.

Study Five investigated the relationship between post-school day occupations and young persons change in behaviour overtime. Mental functions, including global psychosocial, temperament and personality, emotional and higher-level cognitive functions are classified within the Body Functions and Structures component of the ICF and best describe behaviour (World Health Organization, 2001). Therefore, this study was classed as being aligned within the Body Functions and Structures component for the purpose of this thesis.

Young people with Down syndrome have been reported as experiencing fewer behaviour problems than those with other intellectual disabilities yet more than the general population. Behaviour problems in young people with Down syndrome have been reported as being associated with poorer maternal mental health and present as a significant issue for families and schools (Bourke et al., 2009). Study Five was longitudinal and investigated the relationship between change in behaviour over a two year period and the day occupations which the young adults attended. The results showed that the young adults with Down syndrome who were attending open employment for two consecutive years were found to experience a decline in behaviour problems in terms of range, intensity and overall problems. Young adults who were attending day recreation programs for two years experienced an increase in range, intensity and overall behaviour problems. Change in psychopatholgy for young people with intellectual disability was examined by Australian researchers revealing that psychopathology was a substantial and persistent comorbidity and effective mental health interventions need to be developed (Einfeld et al., 2006). There is a paucity of research that has examined associations between changing behaviour and other variables. This study offers novel evidence about the potential relationship between participation in open employment and change in behaviour for young people with Down syndrome and highlights the importance of contextual factors.

### 8.1.1 Participation

Understanding participation in its entirety is a challenging task due to the multi-faceted and fluid nature of this concept. The ICF describes participation as 'involvement in a life situation.' This thesis has examined how participation is associated with the other domains of the ICF for young adults with Down syndrome who are transitioning from school to post-school. Study 2 explored the meaning of wellbeing from the perspective of children and youth with disabilities and found that participation or 'having things to do' was a major contributor to their wellbeing. Study Three, Four and Five examined the relationship between different domains of the ICF and participation in post-school day occupations. Study Six examined how other elements of participation, such as participation in social roles, were associated with elements of the environment. The aim of Study Six was to investigate social participation of young adults with Down syndrome and explore its relationship with the social and physical environment.

The qualitative study in this thesis (chapter 3) ascertained children and young peoples' perspectives on what contributed to their wellbeing. One major theme which emerged, described participation. The young people in this study, all of who had disabilities, described the importance of participating in recreational and educational activities and being involved in friendships. The young people also discussed the restricting influence the environment had on their participation, both the physical and attitudinal environment. This study provided the justification and rationale for Study six and assisted to define the research questions. Findings from chapter three are further explored under 'Contextual factors' section of this chapter.

Study Six found that young adults with Down syndrome were reported to have more difficulties participating in social roles (e.g. relationships, community life, recreation etc.) than they did participating in daily activities (e.g. personal care, communication, housing etc.). Interestingly, participation in social roles was found to be more influenced by the physical environment than by the social environment. Additionally, this study found the most commonly reported barriers to participation were attitudes of strangers, lack of support from friends, availability of jobs and public transport. These findings provide clear avenues for intervention which may support young adults with Down syndrome in participation.

Research investigating participation in its entirety for people with Down syndrome is sparse. This thesis has attempted to cover varying aspects of participation including social, community, cultural and workplace participation. Children with intellectual disabilities have been reported to engage in fewer active-physical and skill-based activities compared to their non-disabled peers (King, Shields, Imms, Black, & Ardern, 2013). Other researchers have highlighted the importance of exploring 'with who' the young people with intellectual disabilities are participating in social, recreational and leisure activities (Solish, Perry, & Minnes, 2010). Adolescents with Down syndrome have been reported as participating in more informal activities and often experience exclusion by typically developing peers which limits their involvement in social activities (Wuang & Chwen-Yng, 2012). The need for a change in perceptions in the community was highlighted in a longitudinal Italian study of people with Down syndrome and this thesis has reported a similar need in Australia (Bertoli et al., 2011).

### 8.1.2 Activity

The component Activities and Participation are described together within the ICF. For the purpose of describing findings from specific studies, they will be explained separately in this chapter. Activity is the execution of a task or action by an individual (World Health Organization, 2001). Communication, self-care, and community and social life are described within this chapter of the ICF and are strongly aligned with Study Three in this thesis. The aim of Study Three was to investigate the relationship between functioning in ADL (communication, self-care and community skills) and participation in post-school day occupations.

Factors which influence participation in post-school day occupations for young adults with Down syndrome have been largely unknown. It is known that there is large variation in how young people with Down syndrome function in ADL (Esbensen et al., 2008; Roizen & Patterson, 2003). Some young adults have been reported to be almost independent, living in their own homes, and managing their own daily lives. However, other young adults with Down syndrome are largely dependent on their families and support services to carry out many of their ADL. We hypothesised that level of function in ADL would be related to post-school outcomes with those with better function in ADL being more likely to engage in open employment. This hypothesis was supported with the finding of a strong relationship between post-school day occupation and level of functioning in ADL. Compared with the young adults participating in sheltered employment or day recreation programs, the young adults who participated in open employment or training were more likely to report better functioning in self-care, community and communication skills. Interestingly, we also found that the relationship between behaviour and post-school day occupation was largely accounted for by young person's functioning in ADL.

Functional abilities including self-care, communication and adaptive skills have been reported to slow down in development and decline into midlife for people with Down syndrome (Prasher et al., 1998; Rasmussen & Sobsey, 1994). A more recent longitudinal study in the USA found that functional abilities of people with Down syndrome exhibited patterns of change overtime and provided evidence that developmental change was affected by environmental factors (Esbensen et al., 2008). Bertoli and colleagues (2011) suggested that lack of employment opportunities may contribute to the loss of acquired skills. This thesis fills an obvious gap in the literature by providing evidence of the strong relationship between post-school day occupation and functioning in ADL.

### 8.1.3 Contextual factors

The ICF describes two components of contextual factors, environmental factors and personal factors. Personal factors include the particular background of an individual's life and living and involve features that are not part of a health condition or health state (World Health Organization, 2001). Within this thesis, personal factors explored were mainly age and gender. Quality of life has also been presented as a personal factor (Huber, Sillick, & Skarakis-Doyle, 2010). Environmental factors are factors which interact with components of the body functions and structures and activities and participation. Immediate family and extended family are factors of the environment which have the potential to influence the level of disability a person with Down syndrome experiences.

Study Four of this thesis examined the relationship between family quality of life and young persons' participation in post-school day occupations. The majority of young adults with Down syndrome live with their families well into adulthood highlighting the importance of the quality of the family life. Study Four aimed to explore the relationship between family quality of life, day occupations and activities of daily living for young persons with Down syndrome. This study employed a cross-sectional methodology and involved both quantitative and qualitative data. Findings revealed that families of young people participating in open employment reported better family quality of life than those in sheltered employment, however the presence of family support reduced the association. We also found that those who were more able in activities of daily living were more likely to have families who report higher family quality of life. Research investigating family quality of life is a relatively recent field of study and emerged in response to the need to understand and develop family-centred approaches to care for people with intellectual disabilities (Brown & Brown, 2004). Further research needs to examine components of the young persons' life and associations with overall family quality of life. Identifying components of the young person's life which are associated with family quality of life has the potential to provide clear avenues for services to achieve family-centred approaches (Brown & Brown, 2004).

It has been argued that no description of a person's health state is complete without reference to quality of life (World Health Organisation, 2001). Huber and colleagues (2010) described the ICF as a biospsychosocial model that takes an individual's experience with illness or disability at its central tenant and point out that there is a need for uniting the concepts of an individual's personal experience, with their disability and their quality of life. Quality of life has been suggested to fit within the personal factors component by German researchers who proposed six chapters of categories for this component (Grotkamp, Cibis, Nuchtern, von Mittelsaedt, & Seger, 2012). Measurement tools for assessing young adults, who have intellectual disabilities, quality of life are emerging and allowing for both proxy and self-report (e.g. Personal Outcomes Scale: Claes, Van Hove, van Loon, Vandevelde, & Schalock, 2009). This thesis reported on the meaning of wellbeing from the perspective of children and young people with disabilities, but did not specifically measure quality of life.

The terms quality of life and wellbeing have been described interchangeably in research, however they are not synonymous. According to the World Health Organization Quality Of Life Group (WHOQOL) quality of life is defined as ‘an individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concern’ (The WHOQOL Group, 1995). Wellbeing has been described to involve two constructs, the individuals’ expression of positive or negative emotions or mood, and the individuals’ general satisfaction with aspects of his/her life (Diener, & Suh, 1997). The qualitative study in this thesis explored the meaning of wellbeing from the perspective of children and young people with disabilities. They discussed their satisfaction with aspects of life including participation, family, relationships and friendships. Overall the meaning of wellbeing which emerged from their perspective’s involved the young people feeling supported, included and respected, as well as feeling valued and capable.It is now well reported that self-reports of wellbeing in people with mild intellectual disabilities should be underlined and prioritised (Lucas-Carrasco, & Salvador-Carulla, 2012; Hulbert-Williams, Hastings, Crowe, & Pemberton, 2011). Further research should address the challenges of gaining self-report of people with severe intellectual disabilities. This point is addressed further in ‘Recommendations for future research.’

## 8.2 Limitations

This thesis drew on a population-based longitudinal database to examine the experience of transition from school to post-school and explore post-school life for young adults with Down syndrome in Australia. There were a number of limitations in this research relating to management of data, application of the guiding theoretical framework and defining and measuring complex concepts such as family quality of life and participation. Implications of these limitations will be discussed.

The ICF as a guiding framework for this research provides a universal language for describing health and health related states, from the perspective of the body, the individual and society (World Health Organization, 2001). Locating measurement tools which measured each of the domains of the ICF in their entirety proved difficult, as others have reported (Hammel et al., 2008; Verdonschot et al., 2009b). It has become difficult for researchers to choose the most appropriate outcome measures for specific research questions due to the large number of often competing, condition-specific and generic instruments which have been developed (Cieza, Brockow, Ewert, Amman, Kolleritis, et al., 2002; Cieza, Geyh, Chatterji, Kostanjsek, Ustun, et al., 2005; Stucki, & Cieza, 2004). In attempting to measure the environment component of the ICF, a limitation arose. Chapter 7 of this thesis presented a study which examined the relationship between participation in social roles and the influence of the physical and/or social environment. The MQE was used to measure the influence of the environment on participation, and the items in the measure mapped well to the codes in the environment component of the ICF (World Health Organization, 2001; Fougeyrollas, Noreau, St-Michael, & Boschen, 1999). However, the MQE classified the role of community organisations, recreational facilities and religious organisations as elements of the physical environment, whereas this may not be the case in the ICF (Fougeyrollas, Noreau, St-Michael, & Boschen, 1999; World Health Organization, 2001). To account for this, readers were reminded to interpret the results in the context of this limitation and infer the definition of the physical environment as per the MQE (Fougeyrollas, Noreau, St-Michael, & Boschen, 1999).

Assessing the complex construct of family quality of life was another challenge of this research. As others have highlighted, measuring family quality of life presents difficulties in defining the term family, whether to use one or multiple perspectives (e.g. mothers, fathers, siblings perspectives) and if multiple perspectives were employed, how would these data be managed statistically (Summers, et al., 2005; Park et al., 2003; Crowley, & Taylor, 1994). Also, for families of children and young people with intellectual disability, the involvement of the person with intellectual disability in offering their own subjective perspectives on family quality of life presents challenges (Beadle-Brown, Murphy, & DiTerlizzi, 2009; Bonham, Baseheart, Schalock, Marchand, Kirchner, & Rumenap, 2004). Research has shown that there are key elements of quality of life only captured by the subjective perceptions of people themselves (Stancliffe, 2000; Schalock, Brown, Brown, Cummins, Felce, et al., 2002; Cummins, 2005; Claes, Vandevelde, Van Hove, von Loon, Verschelden, et al., 2012). In this thesis both quantitative and qualitative data were employed to assess and analyse family quality of life. However, this research was limited by the fact that young people with Down syndrome were not directly involved in defining the quality of life of their families.

The measurement tools employed in 2004 and 2009 were specified prior to the commencement of this PhD (see ‘Candidates role’ section of chapter 1 for more details). To allow for longitudinal data analysis, some of the measures to be included in the 2011 wave of questionnaires were pre-defined by the fact that there were already data collected in 2004 and 2009. The measures already included were not necessarily the ‘gold-standard’ in 2011, as new tools may have been developed or improved versions of existing measures released. However, it would have been detrimental to the longitudinal study to change the measures after two waves of data collection (Hartge, & Cahill, 2008). Also, longitudinal research introduces the possibility of survival bias and non-response bias, which could have potentially influenced this research (Hartge, & Cahill, 2008). Noteworthy, were the response fractions in this study. They remained above seventy percent, minimising the influence of either of these biases.

One other possible limitation of this research was the fact that the data from the Down syndrome NOW database were parent report. This limitation is specifically relevant to parent report data about their young persons' psychopathology and family quality of life (Douma et al., 2006; Haynes et al., 2013). However, gaining self-report data from young adults with intellectual disability presents more challenges (Nind, 2008; Scott et al., 2013). These difficulties include communicating abstract ideas to participants, enabling participants to express their views and share their experience, and ways of acting inclusively (Nind, 2008). There is a need for appropriate and rigorous instruments that enable young adults with intellectual disability, especially severe intellectual disability, to report on their own emotions and quality of life (Douma et al., 2006; Haynes et al., 2013).

Data were collected from only one state of Australia, Western Australia. Whether these findings are generalizable to reflect young adults with Down syndrome from other states of Australia is debatable. Perth is the fourth largest city and the second fastest growing city in Australia. One area which may differ between states was types of services available and service utilisation. State and territory service use of people with disability who may need disability support services, ranged from 20% to 50% across Australia in 2010-11. The proportion of people with a disability who used open employment support services increased across all states in Australia to 7.1% in 2010-11 from 5.9% in 2008-09 (COAG Reform Council, 2013). Rates of use of supported employment services or sheltered employment services were reported to be highest in South Australia (16.0%) and Tasmania (10.6%) and lowest in the Northern Territory (3.2%) (Western Australia approximately 8%). Although service use differs slightly across Australia, the proportion of service use in general is quite low and could be argued as a reason that the findings from this thesis could be generalizable across Australia (COAG Reform Council, 2013). Further research needs to examine the influence service use has on outcomes for young people with intellectual disability.

## 8.3 Recommendations

### 8.3.1 Recommendations for service delivery

This thesis presents evidence which can be utilised to guide clinical practises and develop policy for young people with intellectual disability who are transitioning from school to adulthood. The timing of this thesis parallel with the introduction of DisabilityCare Australia ensures up to date and relevant information about the current experience of transition for young people with Down syndrome living in Western Australia. This thesis has enabled the examination of the association between various domains of the ICF and post-school outcomes.

Improving functioning in activities of daily living has been shown to be a key component in increasing the likelihood that a young person with Down syndrome participates in open employment. Improving functioning in ADL such as self-care, communication and community skills is often the focus of therapy interventions delivered by Occupational Therapists and Speech Pathology. Occupational Therapists believe that development of ADL and instrumental ADL skills are some of the most important occupations acquired by children and young people as they mature (Case-Smith, 2005). Occupational Therapists are therefore well placed to facilitate the development of these skills for young people with Down syndrome. In July 2011 in Australia, the Better Start for Children with Disability initiative was launched. Better Start provides access to funding for children (under the age of seven years) with Down syndrome and other disabilities for early intervention therapies (Australian Government., 2013). Young people with Down syndrome are now able to access these services, along with other relevant services which aim to improve ADL such as PEBBLES Continence Management. This thesis has highlighted the importance of targeting skills of ADL in order to improve functioning and increase likelihood for post-school participation in open employment. Young people with Down syndrome may benefit from participation in Occupational Therapy with the aims of improving functioning in ADL.

This thesis has shown an association between better functioning in ADL and higher family quality of life. Although no other studies have investigated the family quality of life of families of young people with Down syndrome transitioning from school to post-school, research has shown that parents of young people with Down syndrome experience poorer mental health than the general population (Bourke et al., 2009). Identifying potential avenues to improve the mental health of parents and therefore potentially family quality of life needs to become a focus of research. As mentioned in the previous paragraph, Occupational Therapists have the potential to facilitate improvement of functioning in ADL for young people with Down syndrome. The benefits to improving functioning in ADL for young adults with Down syndrome are likely to be at least two-fold, increasing likelihood for participation in open employment and higher family quality of life.

Behaviour problems in young people with Down syndrome have been reported to be associated with the young people having fewer friends and poorer maternal mental health (Bourke et al., 2009; Oates et al., 2009). This thesis investigated the relationship between change in behaviour for young people attending different day occupations. The young people who were attending open employment were reported as exhibiting less behaviour problems over the two years compared with young people attending the other day occupations. Research comparing young people with intellectual disability who were attending mainstream schooling or segregated schooling found that those in mainstream schooling had more ambitious work-related aspirations (Cooney, Jahoda, Gumley & Knott, 2006). One reason for this could be the modelling of behaviours and attitudes towards future work from their typically developing peers. Cooney and colleagues (2006) as well as other authors discuss the important influences social influence can have on the self-perceptions and future wellbeing of young people with intellectual disabilities (Wehmeyer & Garne, 2003; Dagnan & Sandhu, 1999). This study has extended these discussions to include the potential influence peer interactions and environment can have on change in behaviour.

The findings from this study support Bandura's theory of social learning regarding role models as a powerful influence on behaviour (Bandura, 1977; Bandura, 1997). For typically developing young people, it is known that they practise and refine social skills, access support systems and learn peer norms, values and socially appropriate behaviours as a result of peer relationships (Hartup, 1999; Rubin, Bukowski & Parker, 1998). The young adults with Down syndrome in this study may have developed social relationships with typically developing young people in the open employment environment which could explain some improvement in behaviours. A review investigating evidence related to interventions which could increase social interactions among adolescents with intellectual disability and their typically developing peers highlights the important role of both social competence and environmental factors (Carter & Hughes, 2005). This study has shown that these theories may be applied to young adults with Down syndrome and that the role of the environment, can be just as important as the role of social skills training in developing social relationships and improving behaviour (Bandura, 1977; Carter & Hughes, 2005). This provides important information for services that provide behaviour interventions to people with intellectual disabilities. Interventions should incorporate elements of this theory such as providing opportunities for people with Down syndrome to model, observe and imitate behaviours from their typically developing peers. The important influence which environmental factors have on other components outlined in the ICF is becoming apparent in the literature (Schneidert et al., 2003; Verdonschot et al., 2009b). This thesis adds to this body of knowledge by specifically highlighting the importance an open employment environment in change in behaviour for young people with Down syndrome.

A considerable concern which needs to be addressed in Australia is the finding that community attitudes continue to act as a barrier to participation for young people with Down syndrome. Public awareness campaigns need to be launched to ensure disability awareness and education for the Australian general public. The UNCRPD promotes the 'full realisation of all human rights and fundamental freedoms for all persons with disability without discrimination of any kind on the basis of disability' (United Nations, 2006). The perspectives of parents of young adults with Down syndrome presented in this thesis suggests that there needs to be a focus on changing attitudes of the general public which could have a considerable influence on increasing participation for young people with Down syndrome.

### 8.3.2 Recommendation for knowledge translation

Unsuccessful or lack of translation of clinical and health service research into practise and policy has been consistently reported, leading to less than optimal care and support for consumers (Grimshaw et al., 2012; Graham, Foy, Robinson, Eccles, Wensing et al., 2008; McGlynn, Asch, Adams, Keesey, Hicks et al., 2003; Estabrooksm, Derkson, Winther, Lavis, Scott, et al., 2008). The introduction of the UNCRPD and initiatives such as the Incheon Strategy highlight the importance of minimising the evidence-practise and policy gaps (United Nations, 2006; United Nations, 2012). Participation in work and employment, education, living independently, participation in cultural life, recreation, leisure and sport and the right to home and family are human rights listed by the UNCRPD which need to become realities for people with Down syndrome. This thesis offers evidence which could play a role in facilitating the actualisation of these rights, specifically to do with work and employment and participation in cultural life, recreation, leisure and sport.

Throughout this research, the author has attempted to take part in activities which aim to translate research findings into practise (see pages xvi to xx of this thesis). These include presentation of findings at scientific and non-scientific conferences.

Presentation of findings to representatives from service providers including families and community members. Publication of six journal articles in scientific journals. A lay summary information booklet was written and mailed to all participants in the Down syndrome NOW study and shared with local service providers.

This research was guided by a consumer reference group of mothers of young adults with Down syndrome. Collaborating with consumer and community reference groups is now an expected component of health and medical research and has been reported to add a valuable contribution to research from both the consumers and the researchers perspectives (Boote, Telford, & Cooper, 2002; South, Fairfax, & Green, 2008; Payne et al., 2011; National Health and Medical Research Council, 2002). The mothers in the consumer reference group offered their experiential expertise and assisted to interpret the results of analysis. Specifically, the mothers offered a unique perspective and drew attention to issues which the researchers may not have been aware (Thompson, Barber, Ward, Boote, Cooper et al., 2009). Consistent consultation with the consumer reference group in this study has ensured connection with the community increasing likelihood the research will be relevant and useful in translation to policy and service provision.

Additionally, this research was undertaken in partnership with Disability Services Commission, Down syndrome WA, the Department of Education and specific employment support services in Western Australia. Input from these groups added valuable contribution to the research, in order to provide evidence-based information to potentially influence policy change. Results and outcomes of this thesis have been shared with these organizations to provide them with information to improve their services, or be encouraged to know that their organizations are providing services based on evidence.

### 8.3.3 Recommendations for future research

This thesis has shown the importance of better functioning in ADL and identified that Occupational Therapists may have the skills to facilitate improvements in this area. However, there is a lack of evidence, specifically Randomised Controlled Trials (RCT) which have evaluated the effectiveness of Occupational Therapy in improving functioning in ADL. RCTs investigating the relationship between an Occupational Therapy programs and improved functioning in ADL are required for young people with Down syndrome. Research has shown that interventions designed for people with Developmental Disorders have had a differential effect for those with Down syndrome (Yoder & Warren, 2002). This differential effect could be due to a number of reported differences between people with Down syndrome and people with others types of developmental disabilities. People with Down syndrome have been reported to be associated with higher risks of certain conditions, including overweight, obesity and related health problems (Melville, Cooper, Morrison, Allan, Smiley, et al., 2008; Anderson, Humphries, McDermott, Marks, Sisirak, et al., 2013). Also, research has found that children with Down syndrome use fewer requests but the same number of comments compared to other children with intellectual disability. An explanation was presented by Yoder and Warren that this may be due to hypotonicity and consequent passivity (2002). Children and young people with Down syndrome were reported to exhibit more hypotonicity and passivity than others with intellectual disability matched for developmental level (Linn, Goodman, & Lender, 2000; Kumin, & Bahr, 1999). Due to these differences, future research should target investigations of interventions specifically for people with Down syndrome.

The first study in this thesis and a recent qualitative study employing focus groups to gain the perspective of young people with Down syndrome have shown that research from the perspectives of children and young people with disabilities is possible and provides interesting and useful results (Foley, Blackmore, et al., 2012;

Scott et al., 2013). Another study has included people with Down syndrome as co-researchers in a participatory action research study were they were employed to analyse qualitative data (Stevenson, 2014). This was one of few studies were people with intellectual disability were involved in the analysis phase of a research project (Richardson, 2002; Goodley, & Lawthorn, 2005). The authors suggested that inclusion of people with intellectual disability in the analysis phase has the potential to yield interesting and fruitful results (Stevenson, 2014). This approach reflects a collective emphasis on people with intellectual disability being respected with equal rights and being included in all aspects of community life (Martin, 2006; Harrison, Johnson, Hillier, & Strong, 2001). There is strong support for the efficacy of facilitating young people with intellectual disability to develop skills to become self-determined (Wood, Fowler, Uphold, & Test, 2005; Cobb, Lehman, Newman-Gonchar, & Alwell, 2009). The core elements of self-determination have been described to include autonomy, self-realisation and psychological empowerment (Shogren, Kennedy, Dowslett, & Little, 2014). Inclusion of people with intellectual disabilities in the design and implementation process of research provides an avenue to facilitate the development of self-determination. The importance of continuing to involve young people with intellectual disabilities, including mild moderate and severe intellectual disabilities, in research and in the development of policy should be a goal of future research and policy development. This is mentioned in the UNCRPD by outlining that there must be a member on the Committee on the Rights of Persons with Disabilities with a disability (United Nations, 2006).

Longitudinal research which investigates predictors of social participation for young people with Down syndrome is required. This thesis has provided insights into the relationship between social participation and factors within the environment. Findings from Study Five showed that altering the influence of the physical environment has the potential to positively influence social participation. Further knowledge on factors during childhood or early adolescence which may predict social participation in adulthood would be invaluable to ensuring increased participation for adults with Down syndrome.

### 8.4 Concluding comments

The increased life expectancy for people with Down syndrome alongside decreased presence of impairments and improvements in overall health has led to an exciting time of opportunity for people with Down syndrome (Thomas et al., 2010). The challenge is now to improve quality of life and wellbeing for these young people and their families. People with Down syndrome are rightfully expecting to participate as full and active citizens in society. This thesis has presented some of the potential benefits of social participation and involvement in open employment for people with Down syndrome. The valuable input people with disabilities and their families can offer to research has been highlighted. The ICF defines participation as 'the involvement in life situations' (World Health Organization, 2001). The relevance and importance of this construct to young people with Down syndrome was highlighted throughout this thesis and confirmed by Harriet, a young girl with Down syndrome, when she was asked about the meaning of wellbeing she said *'the most important thing is, to feel belonged.'*

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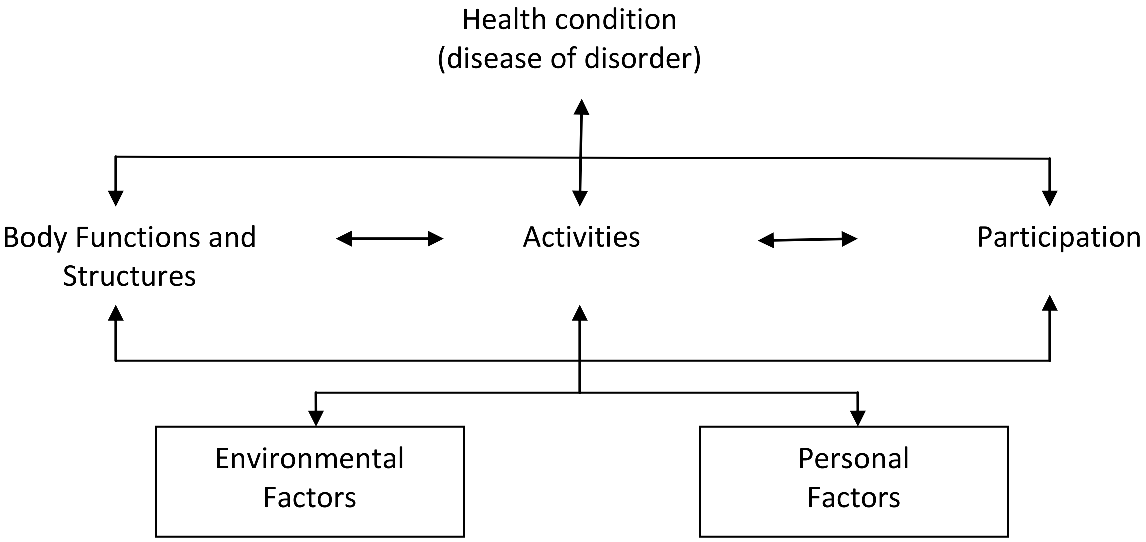
Appendix A: The International classification of functioning, disability and health (World Health Organization, 2001)



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Appendix B: 2004 Down syndrome 'NOW' questionnaire

# DOWN SYNDROME NOW
# NEEDS OPINIONS WISHES
# STUDY
## A questionnaire for parents

Thank you for taking part in this study.

If you have **any** queries about this questionnaire or the study in general, **please** do not hesitate to contact:

**Dr Helen Leonard (Medical Director) or**
Phone: 08 9489 7790
Fax: 08 9489 7700
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**Crystal Laurvick (Project Coordinator)**
Phone: 08 9489 7789
Email: crystall@ichr.uwa.edu.au

# Section 1: Parent Information

*These first questions are to collect some background information about the parents of the child or young adult with Down syndrome.*

1. **Please indicate your relationship to the child who has Down syndrome.**
*Note: If more than one person is filling out the questionnaire, please tick all applicable boxes*

☐ Natural mother
☐ Natural father
☐ Foster mother
☐ Foster father
☐ Adoptive mother
☐ Adoptive father
☐ Stepmother
☐ Stepfather
☐ Other (please specify)__________________________

**Questions 2 - 6 are about the MOTHER of the child with Down syndrome (including the stepmother, foster or adoptive mother if she provides most of the child's care).**

2. **In which country was she born?** ________________________________________

3. **What is her first language?** __________________________________________

4. **What is her date of birth?** _______/_________/_________ **(Day/Month/Year)**

5. **What is the highest qualification that she has completed?**

☐ Primary school
☐ Some high school
☐ Completed high school (Year 12 or equivalent)
☐ Trade or technical qualification (Certificate level)
☐ Advanced diploma
☐ Bachelor degree
☐ Graduate diploma or certificate
☐ Postgraduate degree (Masters or PhD)

6. **Which of the following best describes her current work status?** ***(Please tick all that apply)***

☐ Not working due to her child's disability
☐ Not working for other reasons
☐ Full time homemaker
☐ Looking for work outside the home
☐ Working full or part time (either outside the home or at a home-based business) - Please provide the following information for all jobs currently held:

Job title: __________________________________ Hours worked per week:______

Main tasks: ____________________________________________________

Job title: __________________________________ Hours worked per week:______

Main tasks: ____________________________________________________

**Questions 7 - 11 are about the FATHER of the child with Down syndrome (including the stepfather, foster or adoptive father if he provides most of the child's care).**

**7. In which country was he born?** ______________________________

**8. What is his first language?** ______________________________

**9. What is his date of birth?** ________/__________/__________ (Day/Month/Year)

**10. What is the highest qualification that he has completed?**

☐ Primary school
☐ Some high school
☐ Completed high school (Year 12 or equivalent)
☐ Trade or technical qualification (Certificate level)
☐ Advanced diploma
☐ Bachelor degree
☐ Graduate diploma or certificate
☐ Postgraduate degree (Masters or PhD)

**11. Which of the following best describes his current work status?** ***(Please tick all that apply)***

☐ Not working due to his child's disability
☐ Not working for other reasons
☐ Full time homemaker
☐ Looking for work outside the home
☐ Working full or part time (either outside the home or at a home-based business) - Please provide the following information for all jobs currently held:

Job title: ______________________________ Hours worked per week:______

Main tasks: ______________________________

Job title: ______________________________ Hours worked per week:______

Main tasks: ______________________________

**Questions 12 and 13 are about your child with Down syndrome**

**12. What is your child's date of birth?** ________/__________/__________ (Day/Month/Year)

**13. What is your child's gender?**

☐ Male
☐ Female

**14. In which hospital was your child born? (Please write the state & country if not in WA)**

______________________________

# Section 2: Medical Conditions

*We are interested in finding out how common certain medical conditions are in Down syndrome and how the conditions are treated and managed.*

**1.** **Has your child EVER been diagnosed with a HEART condition such as VSD (ventricular septal defect), ASD (atrial septal defect), Tetralogy of Fallot or another heart condition?**

☐ No - please go to question 2
☐ Yes - please fill out sections a) & b) below

**a) Please indicate in the table below, the name or description of the heart condition(s), whether surgery was performed, and if so, the date the surgery was performed OR the child's age at surgery.**

| Name or description of heart condition | Type of surgery for the condition, if any | Date of OR age at surgery |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**b) Does your child have any current problems or receive continued treatment (including medication) because of the heart condition(s)?**

☐ No - please go to question 2
☐ Yes - please complete the table below

| Current problem | Treatment (If medication, include name, dosage, and frequency) |
|---|---|
| | |
| | |
| | |
| | |

**2.** **Has your child EVER been diagnosed with a BOWEL or GASTROINTESTINAL condition such as Hirschsprung disease, duodenal atresia, an imperforate anus, constipation, reflux or another bowel or gastrointestinal condition?**

☐ No - please go to question 3
☐ Yes - please fill out sections a) & b) below

**a) Please indicate in the table below, the name or description of the bowel or gastrointestinal condition(s), whether surgery was performed, and if so, the date the surgery was performed OR the child's age at surgery.**

| Name or description of bowel or gastrointestinal condition | Type of surgery for the condition, if any | Date of OR age at surgery |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**b) Does your child have any <u>current problems</u> or receive <u>continued treatment</u> (including medication) because of the bowel or gastrointestinal condition(s)?**

☐ No - please go to question 3
☐ Yes - please complete the table below

| Current problem | Treatment<br>(If medication, include name, dosage, and frequency) |
|---|---|
| | |
| | |
| | |
| | |

3. **Has your child EVER been diagnosed with a HEARING or EAR condition such as glue ear, a burst (perforated) ear drum, deafness or another hearing or ear condition?**

☐ No - please go to question 4
☐ Yes - please fill out sections a) & b) below

**a) Please indicate in the table below, the <u>name</u> or description of the hearing or ear condition(s), whether <u>surgery</u> was performed, and if so, the <u>date</u> the surgery was performed OR the child's <u>age</u> at surgery.**

| Name or description of hearing or ear condition | Type of surgery for the condition, if any | Date of OR age at surgery |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**b) Does your child have any <u>current problems</u> or receive <u>continued treatment</u> (including medication) because of the hearing or ear condition(s)?**

☐ No - please go to question 4
☐ Yes - please complete the table below

| Current problem | Treatment<br>(If medication, include name, dosage, and frequency) |
|---|---|
| | |
| | |
| | |
| | |

4. **Has your child EVER been diagnosed with an EYE condition such as short sightedness, squint, cataracts or another eye condition?**

☐ No - please go to question 5
☐ Yes - please fill out sections a) & b) below

**a) Please indicate in the table below, the <u>name</u> or description of the eye condition(s), whether <u>surgery</u> was performed, and if so, the <u>date</u> the surgery was performed OR the child's <u>age</u> at surgery.**

| Name or description of eye condition | Type of surgery for the condition, if any | Date of OR age at surgery |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**b) Does your child have any <u>current problems</u> or receive <u>continued treatment</u> (including glasses) because of the eye condition(s)?**

☐ No - please go to question 5
☐ Yes - please complete the table below

| Current problem | Treatment<br>(If medication, include name, dosage, and frequency) |
|---|---|
| | |
| | |
| | |
| | |

5. **Has your child EVER been diagnosed with a THYROID condition such as an underactive thyroid (hypothyroidism) or an overactive thyroid (hyperthyroidism) or another thyroid condition?**

☐ No - please go to question 6
☐ Yes - please fill out sections a) & b) below

**a) Please indicate in the table below, the <u>name</u> of the thyroid condition(s) and the <u>age</u> at diagnosis.**

| Name of thyroid condition | Age at diagnosis |
|---|---|
| | |
| | |
| | |
| | |

**b) Does your child have any __current problems__ or receive __continued treatment__ (including medication) because of the thyroid condition(s)?**

☐ No - please go to question 6
☐ Yes - please complete the table below

| Current problem | Treatment (If medication, include name, dosage, and frequency) |
|---|---|
| | |
| | |
| | |
| | |

**6. Has your child EVER been diagnosed with a MUSCLE and/or BONE (orthopaedic) condition such as atlantoaxial instability, scoliosis, flat-footedness, or hamstring problems?**

☐ No - please go to question 7
☐ Yes - please fill out sections a) & b) below

**a) Please indicate in the table below, the __name__ or description of the muscle or bone condition(s), whether __surgery__ was performed, and if so, the __date__ the surgery was performed OR the child's __age__ at surgery.**

| Name or description of muscle or bone condition | Type of surgery for the condition, if any | Date of OR age at surgery |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**b) Does your child have any __current problems__ or receive __continued treatment__ (including medication, ankle foot orthoses (AFOs), or braces) because of the muscle and/or bone condition(s)?**

☐ No - please go to question 7
☐ Yes - please complete the table below

| Current problem | Treatment (If medication, include name, dosage, and frequency) |
|---|---|
| | |
| | |
| | |
| | |

**c) Has your child ever had an X-ray of the neck?**

☐ No - please go to Question 6
☐ Yes - Was any abnormality found? ☐ No
☐ Yes - Please describe what was found:

_______________________________________________

7. **Has your child EVER been diagnosed with any OTHER significant health conditions not already mentioned (eg., epilepsy, diabetes, leukaemia, eczema)?**

☐ No - please go to Question 8
☐ Yes - please fill out sections a) & b) below

**a) Please indicate in the table below, the __name__ or description of the other condition(s), whether __surgery__ was performed, and if so, the __age__ at surgery.**

| Name or description of other condition | Type of surgery for the condition, if any | Date of OR age at surgery |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**b) Does your child have any __current problems__ or receive __continued treatment__ (including medication) because of the other condition(s)?**

☐ No - please go to Question 8
☐ Yes - please complete the table below

| Current problem | Treatment (If medication, include name, dosage, and frequency) |
|---|---|
| | |
| | |
| | |
| | |

8. **We are also interested in your child's DENTAL health. Please answer the following questions:**

**a) Has your child had any fillings?**

☐ No
☐ Yes - How many? ____________________

**b) Has your child had any teeth extracted (pulled out)?**

☐ No
☐ Yes - How many? ____________________

**c) Has your child ever had bleeding gums?**

☐ No
☐ Yes - Please indicate how many times____________________

**d) Has your child experienced any other dental problems?**

☐ No
☐ Yes - Please describe ________________________________________

# Section 3: Medical Care, Services and Illness in 2004

*We would like to know how often children and young adults with Down syndrome require medical services and whether you feel your child's medical care needs are being met.*

1. **Please complete the following table relating to the medical or other health care that your child has received SINCE JANUARY 1, 2004 which DID NOT INVOLVE ADMISSION TO HOSPITAL. Please note this table does NOT include visits to allied health therapists (eg., physiotherapists) or alternative therapists (eg., chiropractor, naturopaths) - we will ask you about those later.**

| **Type of practitioner** | **Since 1 January 2004 how many visits has your child had to each doctor or specialist?** | **In a typical year, how often would s/he visit them?** | **Are the visit(s) bulk-billed? (yes or no)**<br>**Note: if there was no charge, write "No cost"** | **What was the total cost of the visit, if known?** | **If the visit was not bulk-billed: How much did you pay for the visit?** | **If you did not pay the total cost, who paid the difference?** |
|---|---|---|---|---|---|---|
| **Example answer** | | | | | | |
| GP or family doctor | 6 | once a month | Yes | $22 | | |
| Disability specialist/ DSC doctor | 3 | once every 3 months | No cost | | | |
| Eye specialist | 1 | once a year | No | $75.40 | $22 | Medicare |
| **Your answer** | | | | | | |
| GP or family doctor (Standard/short visit) | | | | | | |
| GP or family doctor (Long visit) | | | | | | |
| Paediatrician | | | | | | |
| Developmental paediatrician | | | | | | |
| Cardiologist (heart specialist) | | | | | | |
| Neurologist (paediatric or adult) | | | | | | |
| Gastroenterologist | | | | | | |
| Orthopaedic specialist | | | | | | |
| Geneticist | | | | | | |
| Disability specialist/ DSC doctor | | | | | | |
| Eye specialist | | | | | | |
| Ear, nose & throat specialist | | | | | | |
| Podiatrist (foot specialist) | | | | | | |
| Audiologist (hearing specialist) | | | | | | |
| Dentist | | | | | | |
| Dental specialist (eg., Orthodontist) | | | | | | |
| Other:____________ | | | | | | |

2. **Has your child undergone any medical tests SINCE 1 JANUARY 2004 that DID NOT INVOLVE AN ADMISSION TO HOSPITAL? Medical tests may include blood tests, urine tests, X-rays or scans of the body.**

☐ No - please go to Question 3

☐ Yes - please complete the table below to the best of your ability:

| Type of investigation (eg. blood test, Xray) | Since 1 January 2004, how many of these tests has s/he had? | In a typical year, how often would s/he have this test? | What was the total cost of the test, if known? | How much did you have to pay for the test? | If you did not pay the total cost, who paid the difference? |
|---|---|---|---|---|---|
| **Example answer** | | | | | |
| X-ray of neck | 1 | 0 | $65 | $42 | Medicare |
| Blood test (thyroid levels) | 1 | 2 | Not known | $0 | Medicare |
| **Your answer** | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

**Please write any comments you have here:**

3. **Has your child had any medical care that involved DAY admissions or day surgery in hospital SINCE JANUARY 1, 2004? If your child was admitted for a specific procedure, please write the name of the procedure.**

☐ No - please go to Question 4
☐ Yes - please describe the admission(s) in the following table

**DAY STAYS IN HOSPITAL IN 2004**

| Day stay: | Reason for admission | Name of hospital | Public OR Private patient | Name of doctor |
|---|---|---|---|---|
| **Example:** | Grommets | Princess Margaret | Public | Dr N Smith |
| **1st** | | | | |
| **2nd** | | | | |
| **3rd** | | | | |
| **4th** | | | | |
| **5th** | | | | |
| **6th** | | | | |
| **7th** | | | | |

4. **Has your child had any medical care that involved OVERNIGHT stays in hospital SINCE JANUARY 1, 2004?**

☐ No - please go to Question 5
☐ Yes - please describe the admission(s) in the following table

**OVERNIGHT STAYS IN HOSPITAL IN 2004**

| Day stay: | Reason for admission | Number of nights in hospital | Name of hospital | Public OR Private patient | Name of doctor |
|---|---|---|---|---|---|
| **Example:** | Viral infection | 1 | Princess Margaret | Private | Dr S Brown |
| **1st** | | | | | |
| **2nd** | | | | | |
| **3rd** | | | | | |
| **4th** | | | | | |
| **5th** | | | | | |
| **6th** | | | | | |
| **7th** | | | | | |

**Please list any major investigations or procedures s/he had during any of the admissions:**

5. **SINCE JANUARY 1, 2004 has your child had any of the conditions listed in the following table? For each condition that s/he has had, please also indicate the number of episodes of the condition and whether medication was required during an episode.**

| Name of condition | Has your child had the condition? Please tick yes or no | How many episodes of the condition has your child had? | Did your child have medication during the episode? If yes, also record the details in Section 4, Table2. (Please tick boxes) | | |
|---|---|---|---|---|---|
| | | | Episode Number: | Yes | No |
| Cold or flu | ☐ Yes | ☐ 1 | 1st | ☐ | ☐ |
| | ☐ No | ☐ 2 | 2nd | ☐ | ☐ |
| | | ☐ 3 | 3rd | ☐ | ☐ |
| | | ☐ 4 | 4th | ☐ | ☐ |
| | | ☐ 5 | 5th | ☐ | ☐ |
| | | ☐ 6 | 6th | ☐ | ☐ |
| Tonsillitis | ☐ Yes | ☐ 1 | 1st | ☐ | ☐ |
| | ☐ No | ☐ 2 | 2nd | ☐ | ☐ |
| | | ☐ 3 | 3rd | ☐ | ☐ |
| | | ☐ 4 | 4th | ☐ | ☐ |
| | | ☐ 5 | 5th | ☐ | ☐ |
| | | ☐ 6 | 6th | ☐ | ☐ |
| Pneumonia | ☐ Yes | ☐ 1 | 1st | ☐ | ☐ |
| | ☐ No | ☐ 2 | 2nd | ☐ | ☐ |
| | | ☐ 3 | 3rd | ☐ | ☐ |
| | | ☐ 4 | 4th | ☐ | ☐ |
| | | ☐ 5 | 5th | ☐ | ☐ |
| | | ☐ 6 | 6th | ☐ | ☐ |
| Bronchitis | ☐ Yes | ☐ 1 | 1st | ☐ | ☐ |
| | ☐ No | ☐ 2 | 2nd | ☐ | ☐ |
| | | ☐ 3 | 3rd | ☐ | ☐ |
| | | ☐ 4 | 4th | ☐ | ☐ |
| | | ☐ 5 | 5th | ☐ | ☐ |
| | | ☐ 6 | 6th | ☐ | ☐ |
| Episodes of asthma | ☐ Yes | ☐ 1 | 1st | ☐ | ☐ |
| | ☐ No | ☐ 2 | 2nd | ☐ | ☐ |
| | | ☐ 3 | 3rd | ☐ | ☐ |
| | | ☐ 4 | 4th | ☐ | ☐ |
| | | ☐ 5 | 5th | ☐ | ☐ |
| | | ☐ 6 | 6th | ☐ | ☐ |
| Ear infection | ☐ Yes | ☐ 1 | 1st | ☐ | ☐ |
| | ☐ No | ☐ 2 | 2nd | ☐ | ☐ |
| | | ☐ 3 | 3rd | ☐ | ☐ |
| | | ☐ 4 | 4th | ☐ | ☐ |
| | | ☐ 5 | 5th | ☐ | ☐ |
| | | ☐ 6 | 6th | ☐ | ☐ |
| Urinary tract infection | ☐ Yes | ☐ 1 | 1st | ☐ | ☐ |
| | ☐ No | ☐ 2 | 2nd | ☐ | ☐ |
| | | ☐ 3 | 3rd | ☐ | ☐ |
| | | ☐ 4 | 4th | ☐ | ☐ |
| | | ☐ 5 | 5th | ☐ | ☐ |
| | | ☐ 6 | 6th | ☐ | ☐ |
| Other, please describe: | ☐ Yes | ☐ 1 | 1st | ☐ | ☐ |
| ______________ | ☐ No | ☐ 2 | 2nd | ☐ | ☐ |
| ______________ | | ☐ 3 | 3rd | ☐ | ☐ |
| | | ☐ 4 | 4th | ☐ | ☐ |
| | | ☐ 5 | 5th | ☐ | ☐ |
| | | ☐ 6 | 6th | ☐ | ☐ |

6. **Do you feel that the medical care needs of your child have been met?**

☐ Yes
☐ No - please comment on what your child's needs are, and how they could be met:

7. **Do you have any comments about the availability of medical care in your area? (Include comments on any CHANGES to the availability of medical care over the past few years)**

*Questions 8 - 10 ask you about the medical care you received before your child with Down syndrome was born. Specifically, we are interested in your experiences with prenatal screening or testing for Down syndrome.*

8. **Were you OFFERED (ie., given the choice to have) prenatal screening or testing for Down syndrome before your child was born?**

☐ No - please go to question 9
☐ Not sure - please go to question 9
☐ Yes - please complete questions 8a, b and c below:

8a. **Please indicate which of the following tests you were offered (tick all that apply):**

☐ First trimester screening (blood test + ultrasound at 11-13 weeks of pregnancy)
☐ Second trimester screening - also called maternal serum screening or "triple test" (blood test at about 18 weeks of pregnancy)
☐ Diagnostic ultrasound at 18-20 weeks
☐ Chorionic Villus Sampling (CVS)
☐ Amniocentesis

8b. **Were you offered counselling and provided with information about Down syndrome BEFORE deciding whether or not to be tested?**

☐ No
☐ Yes

8c. **In your opinion, were you given adequate information about what the test results would mean before deciding whether or not to be tested?**

☐ Yes
☐ No - please feel free to make any comments below:

**Question 9 should only be answered if prenatal screening/testing was available to you**

**9. Did you CHOOSE to have prenatal screening or testing for Down syndrome before your child was born?**

☐ No - please comment on your reasons in the space below:

☐ Yes - please fill out questions 9a and 9b below

**9a. Please indicate which of the following test(s) you had (tick all that apply):**

☐ First trimester screening (blood test + ultrasound at 11-13 weeks of pregnancy)
☐ Second trimester screening - also called maternal serum screening or "triple test" (blood test at about 18 weeks of pregnancy)
☐ Diagnostic ultrasound at 18-20 weeks
☐ Chorionic Villus Sampling (CVS)
☐ Amniocentesis

**9b. What was the result of the test?** ______________________

**9b. Were you offered counselling and provided with information about Down syndrome following the test result?**

☐ Yes - please feel free to comment below:
☐ No - please feel free to comment below:

**10. Please comment on the benefits and/or drawbacks of prenatal screening/testing for Down syndrome.**

# Section 3a: Evaluation Of Care - Medical Services

*We would like to understand and measure the experiences of parents who have a child with a disability, in relation to the medical care their children receive.*

We would like to know about your perceptions of the overall care you have been receiving **over the past year** from the medical care organisations and practitioners that provide services to your child. These may include your local GP, medical specialists, and hospitals. It does NOT include other kinds of therapy services (e.g., physiotherapy, occupational therapy) - we will be asking about the care you receive from therapy and other services later. Some of the questions included in this questionnaire may not be applicable for the medical practitioners and organisations with whom you have regular contact - if that is the case, simply circle "0" for "not applicable". Also, we realise that there may be some variation in the care you receive from different doctors and organisations, but we are interested in your OVERALL perception of the medical care you and your child receive.

The care that you and your child receive from these people and organisations may bring you into contact with many individuals. The questions in this section are grouped by the type of contact you receive, as described below.

**PEOPLE:** refers to those individuals who work directly with you or your child. These may include GPs and medical specialists (eg., paediatrician, dentist).
**ORGANISATION:** refers to all staff from the medical care organisation, whether involved directly with your child or not. In addition to medical practitioners, they may include support staff such as office staff, housekeepers, administrative staff, etc.

| **In the past year, To what extent do the PEOPLE who work with your child......** | **Indicate how much the event or situation happens to you** | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | to a very great extent | to a great extent | to a fairly great extent | to a moderate extent | to a small extent | to a very small extent | not at all | not applicable |
| 1. help you to feel competent as a parent? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 2. provide you with written information about your child's medical management? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 3. provide a caring atmosphere rather than just give you information? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 4. let you choose when to receive information and the type of information you want? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 5. look at the needs of your "whole" child (eg. at mental, emotional and social needs rather than just at physical needs)? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 6. make sure that at least one team member is someone who works with you and your family over a long period of time? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 7. fully explain treatment choices to you? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 8. provide opportunities for you to make decisions about treatment? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 9. provide enough time to talk so you don't feel rushed? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 10. plan together so they are all working in the same direction? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |

| **In the past year, To what extent do the PEOPLE who work with your child......** | **Indicate how much the event or situation happens to you** | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | to a very great extent | to a great extent | to a fairly great extent | to a moderate extent | to a small extent | to a very small extent | not at all | not applicable |
| 11. treat you as an equal rather than just as the parent of a patient (eg. by not referring to you as "Mum" or "Dad"?) | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 12. give you information about your child that is consistent from person to person? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 13. treat you as an individual rather than as a "typical" parent of a child with a disability? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 14. provide you with written information about your child's progress? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 15. tell you about the results from assessments? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |

| **In the past year, To what extent do the ORGANISATIONS where you receive medical services......** | **Indicate how much the event or situation happens to you** | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | to a very great extent | to a great extent | to a fairly great extent | to a moderate extent | to a small extent | to a very small extent | not at all | not applicable |
| 16. give you information about the types of services offered by the organisation or in your community? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 17. have information available about your child's disability (eg. its causes, how it progresses, future outlook)? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 18. provide opportunities for the entire family to obtain information? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 19. have information available to you in various forms, such as a booklet, kit, video, etc.? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 20. provide advice on how to get information or to contact other parents (eg. parent resource library)? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |

**Please feel free to make any further comments about your overall perceptions of medical care your child receives. Please also comment on any changes to your perceptions over the last few years.**

________________________________________________________

________________________________________________________

________________________________________________________

________________________________________________________

*Acknowledgement: King, Rosenbaum and King, 1997.*

# Section 4: Medication and Supplements

1. Please list in the table below all of the REGULAR medications and supplements that your child is taking. These may be for the treatment of various conditions, such as bowel conditions, thyroid problems, pain, or sleeping problems, or for the everyday health of your child. We would like you to include prescription and non-prescription medications, and vitamin, mineral and food supplements, as well as anything from alternative therapists.

| Name and dosage of medication or supplement | Total dose of medication or supplement given per day (mcg, mg or ml) | How many tablets or mls are in a box or bottle? | How many boxes or bottles do you get per script OR if not a script, per purchase ? | How many days does each box or bottle last? | Is it a prescription medication or supplement? Please tick (yes or no) | How much did you pay for it? |
|---|---|---|---|---|---|---|
| **Example answer** | | | | | | |
| Thyroxine (50 mcg) | 50 mcg 2 times a day | 60 tablets/ bottle | 1 bottle | 30 days | ☑ Yes<br>☐ No | $3.80 |
| Chewable Vitamin C (500 mg) | 500 mg once a day | 60 tablets/ bottle | 1 bottle | 60 days | ☐ Yes<br>☑ No | $11.50 |
| **Your answer** | | | | | | |
| | | | | | ☐ Yes<br>☐ No | |
| | | | | | ☐ Yes<br>☐ No | |
| | | | | | ☐ Yes<br>☐ No | |
| | | | | | ☐ Yes<br>☐ No | |
| | | | | | ☐ Yes<br>☐ No | |
| | | | | | ☐ Yes<br>☐ No | |
| | | | | | ☐ Yes<br>☐ No | |

2. Please list in the table any medications that you have not already listed and that your child may have taken for an acute (short-term) condition SINCE JANUARY 1, 2004. Examples of acute conditions include colds, ear infections, urinary tract infections, pneumonia, bronchitis, tonsillitis, or skin conditions.

| Name of Condition | Name of Medication and dose | How many tablets or mLs in a box or bottle? | Total dose of medication given per day (mg or ml) | How many days did the medication last? | Is it a prescription medication? Please tick (yes or no) | Approximately how much did you pay for it, if known? | Was the medication obtained during a hospital visit for the condition? Please tick (yes or no) |
|---|---|---|---|---|---|---|---|
| **Example answer** | | | | | | | |
| Tonsillitis | Amoxycillin 250mg capsule | 20 | 250mg 4times a day | 5 days | ☑ Yes<br>☐ No | $7.86 | ☐ Yes<br>☑ No |
| Cold | Nurofen for Children | 200mL | 30mL as needed | used for 2 days | ☐ Yes<br>☑ No | about $10 | ☐ Yes<br>☑ No |
| **Your answer** | | | | | | | |
| | | | | | ☐ Yes<br>☐ No | | ☐ Yes<br>☐ No |
| | | | | | ☐ Yes<br>☐ No | | ☐ Yes<br>☐ No |
| | | | | | ☐ Yes<br>☐ No | | ☐ Yes<br>☐ No |
| | | | | | ☐ Yes<br>☐ No | | ☐ Yes<br>☐ No |
| | | | | | ☐ Yes<br>☐ No | | ☐ Yes<br>☐ No |
| | | | | | ☐ Yes<br>☐ No | | ☐ Yes<br>☐ No |
| | | | | | ☐ Yes<br>☐ No | | ☐ Yes<br>☐ No |
| | | | | | ☐ Yes<br>☐ No | | ☐ Yes<br>☐ No |
| | | | | | ☐ Yes<br>☐ No | | ☐ Yes<br>☐ No |

# Section 5: Therapy Services in 2004

*We would like to know how often children and young adults with Down syndrome use the services of therapists. We are also interested in any comments you have about whether your child's therapy needs are being met.*

Your child may receive therapy in a number of ways and from a variety of people.
We would like you to answer questions in relation to therapy during 2004 in 5 settings:

1. Therapy at school
2. Therapy outside of school (with a healthcare professional)
3. Planned therapy at home
4. Incidental therapy at home
5. Recreational and other therapy activities in the community

## THERAPY AT SCHOOL SINCE JANUARY 1, 2004

**1. Has your child had any of the following therapies AT SCHOOL SINCE JANUARY 1, 2004?**

☐ No, s/he **does not** attend school, please go to question 3
☐ No, but s/he **does** attend school, please go to question 3
☐ Yes, please complete the table below to the best of your ability, as we understand that not all parents have this information.

| Type of therapy | Does your child attend the therapy? Please tick yes or no | Number of sessions per week | Duration of session (minutes) | Who is involved in the therapy? | Do you pay for the therapy? If so, how much does it cost on average PER WEEK? |
|---|---|---|---|---|---|
| **Example answer** | | | | | |
| Occupational therapy | ☑ Yes ☐ No | 3 | 30 | Trained therapist | Included in tuition |
| **Your answer** | | | | | |
| Physiotherapy | ☐ Yes ☐ No | | | | |
| Occupational therapy | ☐ Yes ☐ No | | | | |
| Speech/ Communication therapy | ☐ Yes ☐ No | | | | |
| Music therapy | ☐ Yes ☐ No | | | | |
| Hydrotherapy/Swimming | ☐ Yes ☐ No | | | | |
| Horse riding/Hippotherapy | ☐ Yes ☐ No | | | | |
| Gross motor therapy | ☐ Yes ☐ No | | | | |
| Sensory motor therapy | ☐ Yes ☐ No | | | | |
| Behaviour therapy (eg. Applied Behaviour Analysis) | ☐ Yes ☐ No | | | | |
| Other, please describe: | ☐ Yes ☐ No | | | | |
| Other, please describe: | ☐ Yes ☐ No | | | | |

**2. Please feel free to make any comments about therapy services at school. Please include any comments on the availability of therapy services at school.**

________________________________________

________________________________________

## THERAPY OUTSIDE OF SCHOOL SINCE JANUARY 1, 2004

*We are interested in therapies that your child has had with a healthcare professional, including those at a private clinic or as a hospital outpatient.*

3. **Has your child had any of the following therapies OUTSIDE OF SCHOOL SINCE JANUARY 1, 2004?**

☐ No, please go to question 5

☐ Yes, please complete the table below to the best of your ability.

| Type of therapy | Does your child attend the therapy? Please tick yes or no | Number of sessions per week | Duration of session (minutes) | Who does the therapy? AND Where does it take place? | What is the total cost of each visit, if known? | How much do you pay for each visit? | If you do not pay the total cost, who pays the difference? |
|---|---|---|---|---|---|---|---|
| **Example answer** | | | | | | | |
| Speech/ Communication therapy | ☑ Yes ☐ No | 1 | 60 | Speech therapist at private clinic | $40 | $17 | HBF Insurance |
| **Your answer** | | | | | | | |
| Physiotherapy | ☐ Yes ☐ No | | | | | | |
| Occupational therapy | ☐ Yes ☐ No | | | | | | |
| Speech/ Communication therapy | ☐ Yes ☐ No | | | | | | |
| Music therapy | ☐ Yes ☐ No | | | | | | |
| Hydrotherapy/ Swimming | ☐ Yes ☐ No | | | | | | |
| Horse riding/ Hippotherapy | ☐ Yes ☐ No | | | | | | |
| Gross motor therapy | ☐ Yes ☐ No | | | | | | |
| Sensory motor therapy | ☐ Yes ☐ No | | | | | | |
| Behaviour therapy (eg. Applied Behaviour Analysis) | ☐ Yes ☐ No | | | | | | |
| Other, please describe: | ☐ Yes ☐ No | | | | | | |
| Other, please describe: | ☐ Yes ☐ No | | | | | | |

4. **Please feel free to make any comments about therapy outside of school. Please include any comments on the availability of therapy outside of school.**

________________________________________

________________________________________

# PLANNED THERAPY ACTIVITIES AT HOME
# SINCE JANUARY 1, 2004

*We would like to know about planned therapies at home, which are those where time is set aside on a regular basis each week for your child to do their therapy activities at home.*

**5. Has your child had any planned therapy activities AT HOME SINCE JANUARY 1, 2004?**

☐ No, please go to question 7

☐ Yes, please complete the table below to the best of your ability.

| Type of therapy activity | Number of sessions per week | Duration of session (minutes) | People involved in the therapy activity |
|---|---|---|---|
| **Example answers** | | | |
| Practising posture and positions | 4 | 15 | Mum, Dad |
| Practising sounds | 5 | 30 | Mum, sister |
| **Your answer** | | | |
| | | | |
| | | | |
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| | | | |

**6. Please feel free to make any comments about planned therapy at home.**

# INCIDENTAL THERAPY ACTIVITIES AT HOME SINCE JANUARY 1, 2004

*We would like to know about incidental therapies, which are those that you DO NOT specifically set time aside to do with your child, but occur at least weekly as a part of everyday routine.*

**7. Has your child had any incidental therapy activities AT HOME SINCE JANUARY 1, 2004?**

☐ No, please go to question 9

☐ Yes, please complete the table below to the best of your ability.

| Type of incidental therapy activity | Approximate number of times per week | Approximate length of therapy activity (minutes) |
|---|---|---|
| **Example answers** | | |
| Naming objects | 5 | 2 min |
| Making shopping list | 1 | 15 min |
| **Your answer** | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

**8. Please feel free to make comments about incidental therapy activities at home.**

______________________________

______________________________

______________________________

______________________________

# RECREATIONAL AND OTHER THERAPY ACTIVITIES IN THE COMMUNITY SINCE JANUARY 1, 2004

*We are interested to know about recreational and other therapy activities in the community which may be planned or unplanned, and not conducted by a health care professional. The "community" refers to places outside of the home, school or private settings, such as a park or recreational centre.*

**9. Has your child engaged in any recreational or other therapy activities in the community SINCE JANUARY 1, 2004?**

☐ No, please go to the next section

☐ Yes, please complete the table below to the best of your ability.

| Type of recreational/ other therapy activity | How often does s/he do this activity? | Approximate duration of session (minutes) | Location of recreational/other therapy activity | If there is a cost associated with this activity, how much do you have to pay? |
|---|---|---|---|---|
| **Example answers** | | | | |
| Spending time in the park | once a month | 60 min | Local park | No cost |
| Swimming | twice a week | 20 min | Local pool | $5 entry fee |
| **Your answer** | | | | |
| | | | | |
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**10. Please feel free to make comments about recreational and other therapy activities in the community. Please include any comments on the availability of these activities.**

# Section 5a: Evaluation Of Care - Therapy and Other Services

*We would like to understand and measure the experiences of parents who have a child with a disability, in relation to the therapy and other services their children receive.*

We would like to know about your perceptions of the overall care you have been receiving **over the past year** from therapists, therapy organisations, and other people and organisations that provide services to your child. These may include your physiotherapist or speech therapist, therapy organisations such as Therapy Focus, and disability specialist organisations such as the Disability Services Commission. We realise that there may be some variation in the care you receive from different therapists and organisations, but we are interested in your OVERALL perception of the therapy and other services you and your child receive.

The care that you and your child receive from these people and organisations may bring you into contact with many individuals. The questions in this section are grouped by the type of contact you receive, as described below.

**PEOPLE:** refers to those individuals who work directly with you or your child. These may include occupational therapists, speech therapists, local area coordinators, social workers, etc.
**ORGANISATION:** refers to all staff from the organisation, whether involved directly with your child or not. In addition to therapists or other specialists, they may include support staff such as office staff, housekeepers, administrative personnel, etc.

| **In the past year, To what extent do the PEOPLE who work with your child......** | **Indicate how much the event or situation happens to you** | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | to a very great extent | to a great extent | to a fairly great extent | to a moderate extent | to a small extent | to a very small extent | not at all | not applicable |
| 1. help you to feel competent as a parent? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 2. provide you with written information about what your child is doing in therapy? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 3. provide a caring atmosphere rather than just give you information? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 4. let you choose when to receive information and the type of information you want? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 5. look at the needs of your "whole" child (eg. at mental, emotional, and social needs rather than just at physical needs)? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 6. make sure that at least one team member is someone who works with you and your family over a long period of time? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 7. fully explain treatment choices to you? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 8. provide opportunities for you to make decisions about treatment? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 9. provide enough time to talk so you don't feel rushed? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 10. plan together so they are all working in the same direction? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |

| **In the past year, To what extent do the PEOPLE who work with your child......** | **Indicate how much the event or situation happens to you** | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | to a very great extent | to a great extent | to a fairly great extent | to a moderate extent | to a small extent | to a very small extent | not at all | not applicable |
| 11. treat you as an equal rather than just as the parent of a patient (eg. by not referring to you as "Mum" or "Dad"?) | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 12. give you information about your child that is consistent from person to person? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 13. treat you as an individual rather than as a "typical" parent of a child with a disability? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 14. provide you with written information about your child's progress? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 15. tell you about the results from assessments? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |

| **In the past year, To what extent do the ORGANISATIONS where you receive therapy and other services......** | **Indicate how much the event or situation happens to you** | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | to a very great extent | to a great extent | to a fairly great extent | to a moderate extent | to a small extent | to a very small extent | not at all | not applicable |
| 16. give you information about the types of services offered by the organisation or in your community? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 17. have information available about your child's disability (eg. its causes, how it progresses, future outlook)? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 18. provide opportunities for the entire family to obtain information? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 19. have information available to you in various forms, such as a booklet, kit, video, etc.? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| 20. provide advice on how to get information or to contact other parents (eg. parent resource library)? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |

**Please feel free to make any further comments about your overall perceptions of therapy and other services your child receives. Please also comment on any changes to your perceptions over the last few years.**

______________________________________________

______________________________________________

______________________________________________

______________________________________________

*Acknowledgement: King, Rosenbaum and King, 1997.*

# Section 6: Alternative Therapies in 2004

*We would like to know how often children and young adults with Down syndrome use the services of alternative or complementary practitioners.*

1. Please list in the table below all of the alternative or complementary practitioners that your child sees or has seen since January 1, 2004.

   Typical practitioners may include: Chinese medicine or acupuncturists, chiropractors, herbalists, massage therapists, naturopaths, osteopaths, reflexologists, etc.

| Type of practitioner | How often does your child visit them? | How many visits has your child had since 1 January 2004? | What was the total cost of each visit, if known? | How much did you pay for the visit? | If you did not pay the total cost, who paid the difference? |
|---|---|---|---|---|---|
| **Example answer** | | | | | |
| Naturopath | Twice a year | 1 | $45 | $21 | HBF Insurance |
| **Your answer** | | | | | |
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# Section 7: General Disability Services

*We would like to know about the assistance YOU may receive from people in order to help you with your child's care and/or to make it easier for you to care for you child. Please only complete each part if the assistance you receive is related to your child having Down syndrome - for example, you receive household help because you are caring for your child with Down syndrome.*

1. **Please complete the following table relating to the number of hours of PAID personal, household, and general assistance you have or use each week because your child has Down syndrome. If you would like a service but it is not available, please indicate that by putting a tick in the second column. If you receive in-home or out-of-home respite care for your child please write that in Question 3.**

| Type of help or service | Please tick if you want the service but: it is not available or you cannot afford to have the service | Name of organisation which provided the help/service | Total number of hours per week | How much do you pay per hour for this service? |
|---|---|---|---|---|
| **Example answers** | | | | |
| Household tasks | ☐ not available<br>☐ can't afford it | Housework Heroes | 3 | $20/hr |
| Child care for other children, including after school care | ☐ not available<br>☐ can't afford it | Subicare | 9 | about $5/hr<br>($45/day) |
| **Your answer** | | | | |
| Personal care of your child (ie. help with hygiene or dressing) | ☐ not available<br>☐ can't afford it | | | |
| Nursing care for your child | ☐ not available<br>☐ can't afford it | | | |
| Household tasks | ☐ not available<br>☐ can't afford it | | | |
| Gardening tasks | ☐ not available<br>☐ can't afford it | | | |
| Transport to medical or therapy appointments | ☐ not available<br>☐ can't afford it | | | |
| Child care for other children, including after school care | ☐ not available<br>☐ can't afford it | | | |
| Other, please specify: | ☐ not available<br>☐ can't afford it | | | |
| Other, please specify: | ☐ not available<br>☐ can't afford it | | | |
| Other, please specify: | ☐ not available<br>☐ can't afford it | | | |

2. Please complete the following table relating to the number of hours of UNPAID personal, household, and general assistance you have or use each week because your child has Down syndrome. Please tick all boxes that apply and write in the number of hours per week in the last column.

| Type of help | Please tick the box if you would like assistance but it is not available. | Relative(s) Help | Friend(s) help | Volunteer helps | Total number of hours per week |
|---|---|---|---|---|---|
| **Example answers** | | | | | |
| Gardening tasks | ☐ I/we would like it but it is not available | ✓ | | | 1 hr |
| Transport to medical or therapy appointments | ☑ I/we would like it but it is not available | | | | |
| **Your answer** | | | | | |
| Personal care of your child (ie. help with hygiene or dressing) | ☐ I/we would like it but it is not available | | | | |
| Nursing care for your child | ☐ I/we would like it but it is not available | | | | |
| Household tasks | ☐ I/we would like it but it is not available | | | | |
| Gardening tasks | ☐ I/we would like it but it is not available | | | | |
| Transport to medical or therapy appointments | ☐ I/we would like it but it is not available | | | | |
| Child care for other children, including after school care | ☐ I/we would like it but it is not available | | | | |
| Other, please specify: | ☐ I/we would like it but it is not available | | | | |
| Other, please specify: | ☐ I/we would like it but it is not available | | | | |

Please feel free to make any comments about paid or unpaid assistance you receive:

______________________________________________

______________________________________________

______________________________________________

______________________________________________

*We would like to know about respite care that you may use because your child has Down syndrome.*

3. **People caring for a child with Down syndrome may occasionally need 'time-out'. This could involve a variety of things such as someone coming to your house, your child going into respite care for a weekend, or your child going on a respite camp for a few days.**

☐ I HAVE NOT received any respite care, please go to Question 4.

☐ I HAVE received respite care, please answer the following questions.

3a. **Have you received any IN-HOME respite care for your child SINCE JANUARY 1, 2004?**

☐ No, please go to Question 3b.

☐ Yes - How many days of respite care have you received?____________days.

On average, how many hours of care do you receive each time?_________hours.

Do you have to contribute to the cost of this care? Yes ☐ No ☐

If yes, how much does it cost $______________.

Which person(s), agency or organisations provide the care?

_______________________________________________

_______________________________________________

3b. **Has your child been in OVERNIGHT respite care outside the home SINCE JANUARY 1, 2004?**

☐ No, please go to Question 3c.

☐ Yes - How many nights of respite care has your child received?____________nights.

Do you have to contribute to the cost of this care? Yes ☐ No ☐

If yes, how much does it cost $___________.

Where does your child go for respite care? (Please provide the name of the facility)

_______________________________________________

_______________________________________________

3c. **Have you received any other type of care to give you 'time-out' that has not already been mentioned above, SINCE JANUARY 1, 2004 (eg., respite camps for parents)?**

☐ No, please go to Question 3d.

☐ Yes - please describe below:

_______________________________________________

_______________________________________________

_______________________________________________

3d. **Please feel free to make any comments about respite care. Please include any comments about the availability of respite care in your area.**

_______________________________________________

_______________________________________________

4. **As a result of your child having Down syndrome, have you received or used services from support groups or organisations SINCE JANUARY 1, 2004?**

☐ No - please go to Question 6
☐ Yes - please complete the following table as well as Question 5

| Type of service | Name of support group/organisation | Any comments about the service? |
|---|---|---|
| **Example answers** | | |
| Friendship group | Down Syndrome Association of WA | Helpful, especially in early years |
| Babysitter service | Activ Foundation | |
| **Your answer** | | |
| | | |
| | | |
| | | |
| | | |
| | | |

5. **Which of the above groups or organisations has been the most important source of support for you, and why?**

6. **Have you EVER contacted the Down Syndrome Association of WA for support or information?**

☐ No
☐ Yes - please comment on the ways in which the Down Syndrome Association of WA has or has not been a source of support or help for you:

7. **Are you currently a member of the Down Syndrome Association of WA?**

☐ No
☐ Yes

**8. Do you have access to the internet?**

☐ No - please go to Section 8
☐ Yes - please complete Questions 9-11 below

**9. Have you visited the Down Syndrome Association of Western Australia's website? (www.dsawa.asn.au)**

☐ No
☐ Yes, please feel free to make any comments in the space below

**10. Have you visited any other websites relating to Down syndrome (eg. Activ Parent Portal site; Dr Len Leshin's "Down Syndrome: Health Issues" site)?**

☐ No
☐ Yes - please list the websites you have visited, and indicate which of them you found to be useful:

**11. Have you joined a Down syndrome discussion group (e.g., on Yahoo groups)?**

☐ No
☐ Yes, please feel free to make any comments in the space below

# Section 8: Resources, Equipment & Income

*We are interested in understanding what resources and equipment are required to care for your child. Each of the items you list in the following tables will be given a cost, so that we can then work out the costs associated with caring for children and young adults with Down syndrome.*

1. **Does your child use any type of disposable or short-life products that a child without Down syndrome might not need?**

☐ No, please go to Question 2.

☐ Yes, please complete the table below.

**Some examples of products are: nappies or bibs beyond an age when you expect to use them, cleaning cloths/protectors, disposable bed sheets.**

| **Please describe the product** | **What is the total cost of the product, if known?** | **How much do you pay for the product each time you buy it?** | **If you do not pay the total cost, who pays the difference?** | **How many days does the product last you each time you buy it?** |
|---|---|---|---|---|
| **Example answers** | | | | |
| Disposable nappies | $40 | $30 | Continence Aids Assistance Scheme | 14 |
| Wet ones | $6 | $6 | N/A | 7 |
| **Your answer** | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

3. **Have you had any difficulty obtaining any equipment/products IN THE LAST TWO YEARS?**

☐ No

☐ Yes - you may wish to comment in the following space on the difficulties you experienced:

____________________

____________________

____________________

____________________

4. **Do you feel that you receive enough financial support for the equipment/products your child needs?**

☐ No

☐ Yes

☐ Unsure

You may wish to comment in the following space on the availability of financial support for equipment:

____________________

____________________

____________________

____________________

5. **Do you feel that when you need alterations or improvements to equipment/products that it is easy to arrange?**

☐ No

☐ Yes

☐ Unsure

You may wish to comment in the following space on the ease of arranging alterations or improvements:

____________________

____________________

____________________

____________________

*We are interested to know about any health care cards or insurance, and benefits or pensions that you, your spouse, or your child receives because your child has Down syndrome.*

7. **Does the person with Down syndrome have a health care card?** ☐ Yes ☐ No

7a. **Do you have private health insurance for your child with Down syndrome?**

☐ No - please go to Question 8.
☐ Yes - please indicate what level of cover you have:
☐ Hospital only ☐ Extras only ☐ Hospital & Extras ☐ Other:________________

7b. **Did you decide to take out private health insurance because your child has Down syndrome?** ☐ Yes ☐ No

**If yes, what were the reasons for taking out private health insurance?**
*(Please tick all that apply)*

☐ I believe the family needs private health insurance because we have a child with Down syndrome.
☐ I believe that the level of care will be better with private health insurance.
☐ I started cover so we don't have to be on waiting lists.
☐ I increased our level of cover so we receive benefits for more health services.
☐ Other:__________________________________________________

8. **If you, your spouse/partner, or child are receiving any benefits or pensions, please write the NUMBER OF EACH that you receive in the corresponding boxes below.**

**Unemployment allowance** ☐
**Age pension** ☐
**Disability support pension** ☐
**Mobility allowance** ☐
**Education allowance** ☐
**Mature age allowance** ☐
**Department of Veteran Affairs** ☐

**Parenting payment (single)** ☐
**Parenting payment (partnered)** ☐
**Sickness allowance** ☐
**Special benefit** ☐
**Carer allowance (formerly called the Child Disability Allowance for children under 16)** ☐
**Carer payment** ☐
**Other:**____________________ ☐
**Other:**____________________ ☐

9. **Which words best describe your family's money situation?** (Tick the box that best applies to you)

- ☐ We are spending more money than we get
- ☐ We have just enough money to get us through to the next pay day
- ☐ There's some money left over each week but we just spend it
- ☐ We can save a bit every now and again
- ☐ We can save a lot

10. **What do you estimate the combined gross parental income (before tax) was in 2003, not including benefits and pensions? (Please tick only one box)**

| | | | |
|---|---|---|---|
| **Less than $20,800** | ☐ | **Between $36,400 and $41,599** | ☐ |
| **Between $20,800 and $25,999** | ☐ | **Between $41,600 and $51,999** | ☐ |
| **Between $26,000 and $31,199** | ☐ | **Between $52,000 and $77,999** | ☐ |
| **Between $32,000 and $36,399** | ☐ | **$78,000 or more** | ☐ |
| | | **I prefer not to answer this question** | ☐ |

11. **To what extent is dependable transport BY CAR (own car or provided by others) adequate for your family?** *(Please tick one box)*

- ☐ Not at all adequate
- ☐ Seldom adequate
- ☐ Sometimes adequate
- ☐ Usually adequate
- ☐ Almost always adequate
- ☐ Not applicable

12. **To what extent is dependable PUBLIC transport (eg., buses, trains) adequate for your family?** *(Please tick one box)*

- ☐ Not at all adequate
- ☐ Seldom adequate
- ☐ Sometimes adequate
- ☐ Usually adequate
- ☐ Almost always adequate
- ☐ Not applicable - we always use private transport

13. **Please write any comments you may have about this resources, equipment and income section here:**

________________________________________________

________________________________________________

________________________________________________

________________________________________________

14. **Please write in the date that you completed this section:______/_____/2004.**

# Section 9: Puberty

*We are interested in your child's physical and emotional development during adolescence, and whether there is/was anything particularly unusual or difficult about this period.*

**This section only needs to be filled out if your child is 12 YEARS OR OLDER.**
**If your child is younger than 12 years, please go to Section 10.**

1. **Has your child begun to display signs of puberty (eg., growth of pubic hair, breast budding, enlargement of testes)?**

   ☐ No
   ☐ Yes - Please write the age of your child when you began to notice these changes: ______

2. **Is there anything about your child's sexual development that you would consider to be unusual or different from what you would expect for his/her age?**

   ☐ No
   ☐ Yes - please describe in the following space:

3. **Is there anything about your child's social and emotional development or behaviour during puberty that you would consider to be unusual or different from what you would expect for his/her age, or that you need/needed to handle in a different way because your child has Down syndrome?**

   ☐ No
   ☐ Yes - please describe in the following space:

4. **Does your child use any methods of contraception?**

   ☐ No
   ☐ Yes - please describe which method(s) and feel free to make any further comments:

5. **Please comment on any other issues arising during puberty.**

**Questions 6-10 only need to be filled out if your child is FEMALE.**
**If your child is male, please go to Section 10.**

**6. Has your daughter started having menstrual periods?**

☐ No - please go to Section 10
☐ Yes

**7. How old was your daughter when she started her periods?**

Date / / or aged ____ years &____ months

**8. Do you have or have you ever had any problems with your daughter's menstrual periods?**

☐ No
☐ Yes, please feel free to make any comments about variations in functioning, symptoms, any aspect of your daughter relating to her menstrual cycle (eg. seizure activity) and about how you manage her periods.

**9. Is your daughter on any medication to manage her menstrual periods?**

☐ No
☐ Yes, please provide details below:

**10. Has she had any surgical procedures in relation to her periods or to any other gynaecological problem?**

☐ No
☐ Yes, please describe the procedures in the following table:

| Type of surgery | Date of OR age at surgery |
|---|---|
| | |
| | |
| | |
| | |

# Section 10: Early Care, Schooling & Post School Options

*We are interested in knowing what types of schooling or care are received by children and young adults with Down syndrome.*

1. **Please indicate whether your child is:**

☐ Younger than school age (and NOT attending kindergarten or pre-school) - please go to question 2

☐ Attending kindergarten, pre-school or school - please go to question 5

☐ No longer at school - please go to question 10

## YOUNGER THAN SCHOOL AGE

2. **Does your child, who is younger than school age, have any current regular care arrangements?**

☐ No, please go to Section 11

☐ Yes, please give details in the following table of your child's current regular care and fill out questions 3 -5 below

| Type of care | Days per week in care | Is there any cost to you in using this type of care? |
|---|---|---|
| **Example answer** | | |
| Community day care | 2 | ☑ Yes - it costs me $46 per day<br>☐ No |
| **Your answer** | | |
| | | ☐ Yes - it costs me__________<br>☐ No |
| | | ☐ Yes - it costs me__________<br>☐ No |

3. **Did you encounter any difficulties organising this care for your child?**

☐ No

☐ Yes - please comment:

________________________________________

________________________________________

________________________________________

________________________________________

4. **Does your child receive any special care or support in the day care setting?**

☐ No

☐ Yes - Do you receive funding for this care or support?

  ☐ No - it costs me ________________________

  ☐ Yes - I receive funding from ________________________

5. **Do you feel that your child's needs are being met under the current arrangements?**

☐ No - please describe what these needs are, and if possible how they could be met, in the space below

☐ Yes - please go to Section 11

☐ Unsure - please comment:

**PLEASE GO TO SECTION 11**

## ATTENDING KINDERGARTEN, PRE-PRIMARY OR SCHOOL

5. **Please give details of your child's current educational placement in the following table.** Please use more than one line if your child attends more than one school.

| Type of school | Type of class | Days per week at school | Aide- proportion of time assisting child at school | Cost of sending your child to this school |
|---|---|---|---|---|
| **Example answer** | | | | |
| Mainstream school | Ed Support Unit | 5 | 80% (4 days) | No cost |
| **Your answer** | | | | |
| | | | | |
| | | | | |
| | | | | |

6. **Do you feel that your child's educational needs are being met under the current arrangements?**

☐ No - please describe what these needs are, and if possible how they could be met, in the space below

☐ Yes

☐ Unsure - please comment:

7. **Over the past few years, there has been a trend towards inclusive schooling (ie., mainstreaming) for children with disabilities. We would like to know your opinion on the benefits and drawbacks of inclusive schooling:**

Benefits:

Drawbacks:

**8. How does your child get TO and FROM school each day that s/he attends?**

| Direction | Monday | Tuesday | Wednesday | Thursday | Friday | What is the total (return) time for the trip? |
|---|---|---|---|---|---|---|
| **Example answer** | | | | | | |
| To School | School bus | School bus | School bus | School bus | School bus | 30 minutes (bus goes one way) |
| From School | Mum drives | Mum drives | Mum drives | Mum drives | Mum drives | 40 minutes (Mum drives to & from school) |
| **Your answer** | | | | | | |
| To School | | | | | | |
| From School | | | | | | |

**9. Please estimate the distance between your home and your child's school (in km):_______________**

PLEASE GO TO SECTION 11

## NO LONGER AT SCHOOL

**10. Does your child currently engage in any regular day activity outside home (NOT including paid employment)?**

☐ No - please go to Question 12

☐ Yes - please give details in the table below :

Please use more than one line if your child attends more than one day activity at the same place.

| Type of place or organisation | Type of activities | Days per week at placement | Is there any cost of this activity to you? |
|---|---|---|---|
| **Example answers** | | | |
| Day Activity Centre | Crafts, movies, cooking | 3 | ☑ Yes - it costs me$20/day<br>☐ No |
| Sister's home | Spends time with family | 1 | ☐ Yes - it costs me_______<br>☑ No |
| **Your answer** | | | |
| | | | ☐ Yes - it costs me_______<br>☐ No |
| | | | ☐ Yes - it costs me_______<br>☐ No |
| | | | ☐ Yes - it costs me_______<br>☐ No |
| | | | ☐ Yes - it costs me_______<br>☐ No |

**11. Do you feel that your child's needs are being met under the current day activity arrangements?**

☐ No - please describe what these needs are, and if possible how they could be met, in the space below

☐ Yes - please go to Question 12

☐ Unsure - please comment:

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

**12. Is your child currently in paid employment, or have they been in paid employment within the last 12 months?**

☐ No - please go to Question 13

☐ Yes - please give details in the table below of all the positions held by your child in the last 12 months, and complete questions 12a - 12d

| Job title | Number of hours per week | Period of employment | Gross annual income |
|---|---|---|---|
| **Example answer** | | | |
| Nursery attendant | 20 | Jan 2004 - present | $15, 000 |
| **Your answer** | | | |
| | | | |
| | | | |
| | | | |
| | | | |

**12a. How did your child secure his/her current job (or his/her most recent job if s/he is no longer employed)?** ***Please tick all that apply***

☐ Through an employment agency (Name of agency:____________________________)

☐ Through friends or family

☐ By independently applying for an advertised position

☐ Other:__________________________________________________

**12b. Did your child undergo training for this job?**

☐ No - please go to Question 12c
☐ Yes - please give details of what this training involved:

**12c. Does your child require ongoing support in this job?**

☐ No - please go to Question 12d
☐ Yes - please give details of what this support involves:

**12d. Please rate your child's level of satisfaction in this job (circle a number).**

| Not at all satisfied | | | | | | | Extremely satisfied |
|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

**Question 13 & 14 should only be answered if your child is NOT currently employed.**
**If your child is currently employed, please go to Question 15.**

**13. Please indicate the main reason(s) why your child is not currently employed** ***(Tick all that apply):***

☐ Not ready for work
☐ Not willing to work
☐ Poor physical health
☐ Changes in funding
☐ Funding not available

☐ No appropriate job vacancies
☐ Has high support needs
☐ Has difficult/challenging behaviours
☐ Problems at previous workplace - Please describe: ____________________
☐ Other: ____________________

**14. Has your child ever attempted to gain employment in the past?**

☐ No
☐ Yes - but s/he was unsuccessful in gaining employment
☐ Yes - s/he was successful in gaining employment but no longer works

**15. Do you feel that your child's employment needs are being met?**

☐ Yes
☐ No - please comment:

**16. Please feel free to make any further comments about employment.**

# Section 11: Accommodation Needs

*We are interested to know where your child currently lives, any plans or expectations you may have to change the current situation in the future, and any issues arising for individuals living in out-of-family-home accommodation.*

1. **Please indicate which of the following options best describes your child's usual place of residence.**

☐ Family home (ie., with parents) - please go to Question 2
☐ Group home or Community Residential Unit - please go to Question 4
☐ Hostel - please go to Question 4
☐ Hospital or nursing home - please go to Question 4
☐ Unit or house, living with other relatives and/or friends - please go to Question 4
☐ Unit or house, living alone - please go to Question 4
☐ Other: ______________________________ - please go to Question 4

2. **What are your plans or expectations about placing your child in out-of-family-home accommodation in the future?** ***(Please tick ONE option only)***

☐ Placement in out-of-family-home accommodation will definitely not be wanted or needed for our child
☐ We may consider out-of-family-home accommodation in the future, but only under extreme circumstances
☐ We are undecided about out-of-family-home accomodation for our child
☐ We may consider out-of-family-home accomodation for our child, but not for the next 20 years or so
☐ We may consider out-of-family-home accomodation for our child in the next 10 years
☐ We may consider out-of-family-home accomodation for our child in the next 5 years
☐ We have been looking at accommodation options for our child - out of interest only at this stage
☐ We have been looking at accommodation options for our child - seriously
☐ We have applied for accommodation funding, and are awaiting the outcome
☐ We applied for accommodation funding, but we were unsuccessful
☐ We have received accommodation funding and are in the process of organising accommodation options for our child

2a. **Please comment in the space below about why you will or will not consider placement in out-of-family home accommodation for your child, and any concerns you may have about it. If you applied for funds but were unsuccessful, please also comment on the reasons given:**

______________________________________________

______________________________________________

______________________________________________

______________________________________________

**2b. If you plan or expect to consider placement in out-of-family-home accommodation for your child in the future, what kind of support services do you think would help extend the period of time your child could stay in the family home?**

**3. Does your child spend time overnight in a place other than the family home on a regular basis?**

☐ No - please go to Question 7

☐ Yes - please indicate where s/he stays, how often, and how much it costs you in the table below:

| Place of accommodation | How often does s/he stay there? | How much does it cost you? |
|---|---|---|
| **Example answers** | | |
| Hostel | 1 weekend per month | $30 per night |
| Aunt's house | 1 night per week | No cost |
| **Your answer** | | |
| | | |
| | | |
| | | |
| | | |

**Questions 4 - 6 are to be filled out only if your child does NOT live in the family home.**
**If your child lives in the family home, please go to Question 7.**

**4. Please indicate which of the following options best describe(s) the reasons why you sought out-of-family-home accommodation for your child.** ***(Please tick all applicable options)***

☐ Change of personal circumstances (e.g., death in family, illness)

☐ Change in service provision (e.g., left school, change in respite services or day activities)

☐ Your child's challenging behaviours were difficult to manage at home

☐ Your child's low level of functioning was difficult to manage at home

☐ Your child wanted to live more independently

☐ Your child moved to be closer to his/her work

☐ Caring for your child at home was causing high levels of stress/exhaustion in your family unit

☐ Caring for your child at home was causing financial difficulties

☐ Family/marital problems

☐ Other:______________________________________________

**4a. Do you think your child would have stayed longer in the family home if you had access to more support services in the home?**

☐ No

☐ Yes - please indicate what kind of services may have extended the period of time that your child stayed at home:

________________________________________

________________________________________

________________________________________

________________________________________

**5. Does your child receive residential care or support (eg., from carers in a group home, or social trainers who visit his/her home regularly)?**

☐ No - please go to Question 6

☐ Yes - please describe who provides the care and how often (eg., carer - 7 days per week)

________________________________________

________________________________________

________________________________________

________________________________________

**6. Does it cost you anything to have your child in out-of-family-home accommodation, including the cost of the accommodation itself, any equipment or supplies used by your child, food or medications?**

☐ No - please indicate who pays for these costs:____________________________

☐ Yes - please describe the type and amount of each cost below (eg., Food - $60 per week):

________________________________________

________________________________________

________________________________________

________________________________________

**7. Do you feel that your child's accommodation needs are being met?**

☐ Yes

☐ No - please comment on what his/her needs are and if possible, how they could be met in the space below:

________________________________________

________________________________________

________________________________________

________________________________________

**8. Please feel free to make any further comments about accommodation.**

________________________________________

________________________________________

________________________________________

________________________________________

**21. How does your child deal with learning new skills or routines? Examples include learning to ride a bike or tie shoelaces, learning to sing a new song, learning how to play a game, or learning how to use a remote control.**

☐ *No help or supervision needed*
- ☐ Your child is able to learn a new skill or routine very quickly without extra help
- ☐ Your child is able to learn a new skill or routine without extra help, but may take longer than others

☐ *Supervision needed*
- ☐ Your child is able to learn a new skill or routine most of the time, but needs extra help or supervision if the task is fairly difficult

☐ *Help needed*
- ☐ Your child can learn a new skill or routine about 75-90% of the time; the rest of time s/he needs extra help or supervision or cannot learn it at all
- ☐ Your child can learn a new skill or routine about 50-75% of the time; the rest of time s/he needs extra help or supervision or cannot learn it at all
- ☐ Your child can learn a new skill or routine about 25-50% of the time; the rest of time s/he needs extra help or supervision or cannot learn it at all
- ☐ Your child can learn a new skill or routine less than 25% of the time; the rest of time s/he needs extra help or supervision or cannot learn it at all

**21a. Please feel free to comment on your child's ability to learn new skills or routines:**

**Questions 22 - 28 should only be completed if your child is 12 YEARS OR OLDER.**
**If your child is younger than 12 years, please go to Section 13.**

**22. How does your child deal with using the telephone? This includes answering the phone, and making phone calls to both familiar and unfamiliar people**

☐ *No help or supervision needed*
- ☐ Your child successfully answers and makes phone calls to/from both familiar and unfamiliar people almost all of the time
- ☐ Your child answers phone calls successfully almost all of the time, and can make phone calls to both familiar and unfamiliar people if s/he prepares what s/he is going to say first (e.g., by writing it down)

☐ *Supervision needed*
- ☐ Your child successfully answers and makes phone calls most of the time, but sometimes requires prompting or assistance with preparation, particularly for phone calls to/from unfamiliar people OR successfully answers and makes phone calls to relatives and friends without supervision but will not make calls to unfamiliar people

☐ *Help needed*
- ☐ Your child successfully answers and makes phone calls to relatives and/or friends about 75-90% of the time; the rest of the time s/he requires help or supervision or will not answer/make the call
- ☐ Your child successfully answers and makes phone calls to relatives and/or friends about 50-75% of the time; the rest of the time s/he requires help or supervision or will not answer/make the call
- ☐ Your child successfully answers and makes phone calls to relatives and/or friends about 25-50% of the time; the rest of the time s/he requires help or supervision or will not answer/make the call
- ☐ Your child successfully answers and makes phone calls to relatives and/or friends less than 25% of the time OR will not use the phone at all

**22a. Please feel free to comment on your child's use of the telephone:**

**23. How does your child deal with using public transport?**
**This includes using buses, trains, ferries and taxis on both familiar and unfamiliar routes.**

☐ *No help or supervision needed*

- ☐ Your child is able to use public transport independently on both familiar and unfamiliar routes
- ☐ Your child is able to use public transport independently on both familiar and unfamiliar routes but you are concerned for his/her safety

☐ *Supervision needed*

- ☐ Your child is able to use public transport independently on familiar route(s), but requires supervision on unfamiliar routes

☐ *Help needed*

- ☐ Your child is able to use public transport on familiar routes about 75-90% of the time; the rest of time s/he needs supervision
- ☐ Your child is able to use public transport on familiar routes about 50-75% of the time; the rest of time s/he needs supervision
- ☐ Your child is able to use public transport on familiar routes about 25-50% of the time; the rest of time s/he needs supervision
- ☐ Your child is able to use public transport on familiar routes less than 25% of the time OR your child always requires supervision when using public transport OR your child refuses to use public transport OR you do not allow your child to use public transport

**23a. Please feel free to comment on your child's use of public transport:**

**24. How does your child deal with domestic duties?**
**This includes putting away personal belongings, washing and drying dishes, making the bed, cleaning floors and washing clothes.**

☐ *No help or supervision needed*

- ☐ Your child successfully completes almost all domestic duties independently
- ☐ Your child completes almost all domestic duties independently, but you are concerned for his/her safety OR s/he takes longer than others OR s/he does not do the tasks as well as others

☐ *Supervision needed*

- ☐ Your child completes most domestic duties independently, but requires supervision for some of the more difficult tasks

☐ *Help needed*

- ☐ Your child completes about 75-90% of his/her domestic duties; for the remainder s/he requires help or supervision
- ☐ Your child completes about 50-75% of his/her domestic duties; for the remainder s/he requires help or supervision
- ☐ Your child completes about 25-50% of his/her domestic duties; for the remainder s/he requires help or supervision
- ☐ Your child completes less than 25% of his/her domestic duties without help OR your child does few or no domestic duties at all

**24a. Please feel free to comment on domestic duties:**

**25. How does your child deal with meal preparation?**
**This includes preparing snacks and cold foods, and cooking meals using stoves, ovens, and microwaves.**

☐ ***No help or supervision needed***

☐ Your child is able to prepare meals independently
☐ Your child is able to prepare meals independently but you are concerned for his/her safety OR s/he takes longer than others

☐ ***Supervision needed***

☐ Your child is able to prepare some meals, but requires supervision or prompting particularly when cooking hot foods

☐ ***Help needed***

☐ Your child is able to complete about 75-90% of the activities involved in preparing meals; for the remainder s/he needs help or supervision
☐ Your child is able to complete about 50-75% of the activities involved in preparing meals; for the remainder s/he needs help or supervision
☐ Your child is able to complete about 25-50% of the activities involved in preparing meals; for the remainder s/he needs help or supervision
☐ Your child is able to complete less than 25% of the activities involved in preparing meals OR does not help with meal preparation at all

**25a. Please feel free to comment on meal preparation:**

**26. How does your child deal with money and managing finances?**
**This includes paying for items using cash, cheque, or credit card, withdrawing money from an ATM or bank, saving money, budgeting for at least 1 week's worth of expenses, and paying bills.**

☐ ***No help or supervision needed***

☐ Your child deals with money and manages his/her own finances independently
☐ Your child deals with money and manages his/her own finances independently, but you are concerned that s/he may be vulnerable to exploitation

☐ ***Supervision needed***

☐ Your child is able to deal with money and manages his/her finances mostly independently, but requires supervision to ensure s/he is managing money sensibly, particularly for difficult tasks such as budgeting

☐ ***Help needed***

☐ Your child completes about 75-90% of his/her finance-related duties; for the remainder s/he requires help or supervision
☐ Your child completes about 50-75% of his/her finance-related duties; for the remainder s/he requires help or supervision
☐ Your child completes about 25-50% of his/her finance-related duties; for the remainder s/he requires help or supervision
☐ Your child completes less than 25% of his/her finance-related duties without help OR your child does not deal directly with money

**26a. Please feel free to comment on your child's management of money and finances:**

**27. How does your child deal with shopping?**
**This includes shopping for groceries at the supermarket or deli, and shopping for other items such as medications, clothes, and household items.**

☐ ***No help or supervision needed***

☐ Your child is able to shop for both groceries and other items independently
☐ Your child is able to shop for both groceries and other items independently, but you are concerned for his/her safety OR s/he does not always choose items sensibly

☐ ***Supervision needed***

☐ Your child is able to shop for both groceries and other items, but requires supervision or prompting particularly when shopping for less regular items

☐ ***Help needed***

☐ Your child is able to complete about 75-90% of shopping activities; for the remainder s/he needs help or supervision
☐ Your child is able to complete about 50-75% of shopping activities; for the remainder s/he needs help or supervision
☐ Your child is able to complete about 25-50% of shopping activities; for the remainder s/he needs help or supervision
☐ Your child is able to complete less than 25% of shopping activities OR does not do any shopping at all

**27a. Please feel free to comment on shopping:**

**28. How does your child deal with social events?**
**This includes going out to dinner, going to the movies, visiting relatives and going out with friends. (Please note this question refers to the social events themselves, not the transport to & from, etc.)**

☐ ***No help or supervision needed***

☐ Your child deals with a range of social events independently
☐ Your child deals with a range of social events independently, but you are concerned for his/her safety

☐ ***Supervision needed***

☐ Your child deals with a range of social events independently, but s/he requires supervision on some occasions, particularly when attending an unfamiliar event or planning an event

☐ ***Help needed***

☐ Your child deals with about 75-90% of his/her social events; for the remainder s/he requires help or supervision
☐ Your child deals with about 50-75% of his/her social events; for the remainder s/he requires help or supervision
☐ Your child deals with about 25-50% of his/her social events; for the remainder s/he requires help or supervision
☐ Your child deals with less than 25% of his/her social events; for the remainder s/he requires help or supervision

**28a. Please feel free to comment on dealing with social events:**

*Acknowledgement: Msall et al, 1994.*

# Section 13: Social Relationships & Activities

*We are interested in your child's friendships and his/her participation in social activities.*

**This section only needs to be filled out if your child is 4 YEARS OR OLDER.
If your child is younger than 4 years, please go to Section 16 of the questionnaire.**

1. **How many close friends does your child have?**

   ☐ None
   ☐ One
   ☐ Two or three
   ☐ Four or more

2. **How often does your child do things with his/her friends (not including activities at school or day care)?**

   ☐ Occasionally
   ☐ Less than once a week
   ☐ Once or twice a week
   ☐ Three or more times a week

3. **Do you feel that having Down syndrome has affected the number and quality of the friendships your child has?**

   ☐ No
   ☐ Yes - please comment on how the friendships have been affected, and the main factors you think may have caused this, in the space below:

____________________________________________________
____________________________________________________
____________________________________________________
____________________________________________________
____________________________________________________

4. **Please list the sports (e.g., swimming, soccer) your child takes part in. If s/he does not participate in any sports, leave the table blank.**

| Sport | Compared to other children without a disability of the same age, about how much time does s/he spend in each one? | | | | Compared to other children without a disability of the same age, how well does s/he do in each one? | | | |
|---|---|---|---|---|---|---|---|---|
| | Less than average | Average | More than average | Don't know | Below average | Average | Above average | Don't know |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

5. Please list your child's hobbies and activities (e.g., books, piano, computers) other than sports (do NOT include listening to music or watching TV). If s/he does not have any hobbies, leave the table blank.

| **Hobby/activity** | **Compared to other children without a disability of the same age, about how much time does s/he spend in each one?** | | | | **Compared to other children without a disability of the same age, how well does s/he do in each one?** | | | |
|---|---|---|---|---|---|---|---|---|
| | Less than average | Average | More than average | Don't know | Below average | Average | Above average | Don't know |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

6. Please answer the following questions based on the TOTAL TIME your child spends doing the following activities in a tyypcal WEEK.

| | Doesn't Usually | Less than 7 hrs each week | About 7-14 hrs each week | Over 14 hrs each week |
|---|---|---|---|---|
| a) How long does your child spend watching TV or videos? | ☐ | ☐ | ☐ | ☐ |
| b) How long does your child spend playing with computer games on the TV (Nintendo, Playstation etc)? | ☐ | ☐ | ☐ | ☐ |
| c) How long does your child spend playing with hand held computer games (Gameboy etc)? | ☐ | ☐ | ☐ | ☐ |
| d) How long does your child spend using a computer (PC or laptop)? | ☐ | ☐ | ☐ | ☐ |
| e) How long does your child spend reading or looking at books? | ☐ | ☐ | ☐ | ☐ |
| f) How long does your child spend drawing, colouring in or writing on paper? | ☐ | ☐ | ☐ | ☐ |
| g) How long does your child run around or play sport or games that make him/her sweat and breathe hard? | ☐ | ☐ | ☐ | ☐ |

7. **Please list any organisations, clubs, teams, or groups your child belongs to. If your child does not belong to any, leave the table blank.**

| **Organisation/club/ team/group** | **Compared to other children without a disability of the same age, how active is s/he in each one?** | | | |
|---|---|---|---|---|
| | Less active<br>☐ | Average<br>☐ | More active<br>☐ | Don't know<br>☐ |
| | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ |

8. **Please describe any benefits you feel that your child brings to any groups, teams or organisations to whom s/he belongs, as well as any other benefits s/he brings to the broader community.**

9. **Do you feel that your child's needs to participate in sports, activities and groups are being met?**

☐ Yes

☐ No - please comment in the space below on what his/her needs are and if possible, how they could be met:

**Questions 10 -12 should be filled out only if your child is NO LONGER AT SCHOOL.**
**If your child is still at school or is younger than school age, go to Section 14.**

10. **Did leaving school affect the number of friends your child has?**

☐ No, same number of friends
☐ Yes, has fewer friends than s/he had at school
☐ Yes, has more friends than s/he had at school

11. **Did leaving school affect the quality of the friendships your child has?**

☐ No
☐ Yes - please comment on how the friendships have been affected in the space below:

12. **Please feel free to make any further comments on the impact of leaving school on your child's social circle.**

# Section 14: Social Communication

**This section only needs to be filled out if your child is 4 YEARS OR OLDER.**
**If your child is younger than 4 years, please go to Section 16 of the questionnaire.**

**a. How does your child communicate?** ***(Tick all that apply)***

☐ Verbally (using speech)
☐ Using sign language
☐ Using a communication aid, eg. Compic, picture board (Please specify:______________________
☐ Non-verbal communication only

**b. How well does your child communicate with others?**

☐ Able to be understood by strangers
☐ Able to be understood by familiar people only
☐ Able to make basic needs known only

**c. How well does your child understand others?**

☐ Always understands
☐ Able to understand most conversations
☐ Able to understand simple conversations and/or follow simple instructions
☐ Able to understand key words only
☐ Demonstrates very little understanding of others

Please answer each of the following questions by circling yes or **no**. A few questions ask about several related types of behaviour: please circle yes if <u>any</u> of these behaviours have <u>ever</u> been present. Although you may be uncertain about whether some behaviours were ever present or not, please answer yes or **no** to every question on the basis of what you think.

1. Is s/he now able to talk using short phrases or sentences? If no, skip to question 8........................ **yes** **no**

2. Can you have a to and fro "conversation" with him/her that involves taking turns or building on what you have said?........................ **yes** **no**

3. Has s/he ever used odd phrases or said the same thing over and over in almost exactly the same way (either phrases that s/he has heard other people use or ones that s/he has made up)?.................. **yes** **no**

4. Has s/he ever used socially inappropriate questions or statements? For example, has s/he ever regularly asked personal questions or made personal comments at awkward times?........................ **yes** **no**

5. Has s/he ever got his/her pronouns mixed up (eg., saying *you* or *she/he* for *I*)?........................ **yes** **no**

6. Has s/he ever used words that s/he seemed to have invented or made up him/herself; put things in odd, indirect ways; or used metaphorical ways of saying things (eg., saying *hot rain* for *steam*)?... **yes** **no**

7. Has s/he ever said the same thing over and over in exactly the same way or insisted that you say the same thing over and over again?........ **yes** **no**

|  |  |  |  |
|---|---|---|---|
| 8. | Has s/he ever had things that s/he seemed to have to do in a very particular way or order, or rituals that s/he insisted that you go through? | yes | no |
| 9. | Has his/her facial expression usually seemed appropriate to the particular situation, as far as you could tell? | yes | no |
| 10. | Has s/he ever used your hand like a tool or as if it were part of his/her body (eg., pointing with your finger, putting your hand on a doorknob to get you to open the door)? | yes | no |
| 11. | Has s/he ever had any interests that preoccupy him/her and might seem odd to other people (eg., traffic lights, drainpipes, or timetables)? | yes | no |
| 12. | Has s/he ever seemed to be more interested in parts of a toy or an object (eg., spinning the wheels of a car), rather than using the object as it was intended? | yes | no |
| 13. | Has s/he ever had any special interests that were *unusual* in their intensity but otherwise appropriate for his/her age and peer group (eg., trains, dinosaurs)? | yes | no |
| 14. | Has s/he ever seemed to be *unusually* interested in the sight, feel, sound, taste, or smell of things or people? | yes | no |
| 15. | Has s/he ever had any mannerisms or odd ways of moving his/her hands or fingers, such as flapping or moving his/her fingers in front of his/her eyes? | yes | no |
| 16. | Has s/he ever had any complicated movements of his/her whole body, such as spinning or repeatedly bouncing up and down? | yes | no |
| 17. | Has s/he ever injured him/herself deliberately, such as by biting his/her arm or banging his/her head? | yes | no |
| 18. | Has s/he ever had any objects (*other* than a soft toy or comfort blanket) that s/he *had* to carry around? | yes | no |
| 19. | Does s/he have any particular friends or a best friend? | yes | no |

For the following behaviours, please focus on the time period between your child's fourth and fifth birthdays. You may find it easier to remember how things were at that time by focusing on key events, such as starting school, moving house, Christmas time, or other specific events that are particularly memorable for you as a family. If your child is not yet 5 years old, please consider his or her behaviour over the past 12 months.

|  |  |  |  |
|---|---|---|---|
| 20. | When s/he was 4 to 5, did s/he ever talk with you just to be friendly (rather than to get something)? | yes | no |
| 21. | When s/he was 4 to 5, did s/he ever *spontaneously* copy you (or other people) or what you were doing (such as vacuuming, gardening, or mending things)? | yes | no |
| 22. | When s/he was 4 to 5, did s/he ever spontaneously point at things around him/her just to show you things (not because s/he wanted them)? | yes | no |
| 23. | When s/he was 4 to 5, did s/he ever use gestures, other than pointing or pulling your hand, to let you know what s/he wanted? | yes | no |

24. When s/he was 4 to 5, did s/he ever nod his/her head to mean *yes*?....... **yes** **no**

25. When s/he was 4 to 5, did s/he ever shake his/her head to mean *no*?..... **yes** **no**

26. When s/he was 4 to 5, did s/he usually look at you directly in the face when doing things with you or talking with you?........................ **yes** **no**

27. When s/he was 4 to 5, did s/he smile back if someone smiled at him/her?........................................................................ **yes** **no**

28. When s/he was 4 to 5, did s/he ever show you things that interested him/her to engage your attention?................................................ **yes** **no**

29. When s/he was 4 to 5, did s/he ever offer to share things other than food with you?.......................................................................... **yes** **no**

30. When s/he was 4 to 5, did s/he ever seem to want you to join in his/her enjoyment of something?................................................ **yes** **no**

31. When s/he was 4 to 5, did s/he ever try to comfort you if you were sad or hurt?........................................................................... **yes** **no**

32. When s/he was 4 to 5, when s/he wanted something or wanted help, did s/he look at you and use gestures with sounds or words to get your attention?..................................................................... **yes** **no**

33. When s/he was 4 to 5, did s/he show a normal range of facial expressions?........................................................................... **yes** **no**

34. When s/he was 4 to 5, did s/he ever spontaneously join in and try to copy the actions in social games, such as *The Mulberry Bush* or *London Bridge is Falling Down*?................................................ **yes** **no**

35. When s/he was 4 to 5, did s/he play any pretend or make-believe games?............................................................................... **yes** **no**

36. When s/he was 4 to 5, did s/he seem interested in other children of approximately the same age whom s/he did not know?........................ **yes** **no**

37. When s/he was 4 to 5, did s/he respond positively when another child approached him/her?....................................................... **yes** **no**

38. When s/he was 4 to 5, if you came into a room and started talking to him/her without calling his/her name, did s/he usually look up and pay attention to you?.................................................... **yes** **no**

39. When s/he was 4 to 5, did s/he ever play imaginative games with another child in such a way that you could tell that they each understood what the other was pretending?.................................... **yes** **no**

40. When s/he was 4 to 5, did s/he play cooperatively in games that required joining in with a group of other children, such as hide-and-seek or ball games?....................................................... **yes** **no**

**Please feel free to make any comments about your child's social skills and/or communication with others.**

*Acknowledgement: Rutter et al., 2003.*

# Section 15: Personality & Behaviour

*We are interested in your child's personality strengths as well as any problems s/he may have with his/her emotions and behaviour.*

**This section only needs to be filled out if your child is 4 YEARS OR OLDER.**
**If your child is younger than 4 years, please go to Section 16 of the questionnaire.**

**a. Please list your child's strengths.**

**b. What do other people like about him/her?**

Many of the following behaviours may not apply to your child. For each item that does describe your child, now or with the PAST SIX MONTHS, please circle the 2 if the item is **very true** or **often true**. Circle **1** if the item is **somewhat or sometimes true** of your child. If the item is **not true** of your child circle the **0**.

**0 = not true as far as you know** **1 = somewhat or sometimes true** **2 = very true or often true**

If your child is unable to perform an item, circle the **0**. For example, if your child has no speech, then for the item "Talks too much or too fast" circle the **0**.

| | Please circle | | | |
|---|---|---|---|---|
| 1. | 0 | 1 | 2 | Appears depressed, downcast or unhappy. |
| 2. | 0 | 1 | 2 | Avoids eye contact. Won't look you straight in the eye. |
| 3. | 0 | 1 | 2 | Aloof, in his/her own world. |
| 4. | 0 | 1 | 2 | Abusive. Swears at others. |
| 5. | 0 | 1 | 2 | Arranges objects or routine in a strict order.<br>Please describe:______________________________ |
| 6. | 0 | 1 | 2 | Bangs head. |
| 7. | 0 | 1 | 2 | Becomes over-excited. |
| 8. | 0 | 1 | 2 | Bites others. |
| 9. | 0 | 1 | 2 | Cannot attend to one activity for any length of time, poor attention span. |
| 10. | 0 | 1 | 2 | Chews or mouths objects, or body parts. |
| 11. | 0 | 1 | 2 | Cries easily for no reason, or over small upsets. |
| 12. | 0 | 1 | 2 | Covers ears or is distressed when hears particular sounds.<br>Please describe:______________________________ |
| 13. | 0 | 1 | 2 | Confuses the use of pronouns, eg. uses "you" instead of "I". |

**0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true**

**Please circle**

14. 0 1 2 Deliberately runs away.

15. 0 1 2 Delusions: has a firmly held belief or idea that can't possibly be true.
Please describe:______________________________________________

16. 0 1 2 Distressed about being alone.

17. 0 1 2 Doesn't show affection.

18. 0 1 2 Doesn't respond to others' feelings, eg. shows no response if a family member is crying.

19. 0 1 2 Easily distracted from his/her task, eg. by noises.

20. 0 1 2 Easily led by others.

21. 0 1 2 Eats non-food items, eg. dirt, grass, soap.

22. 0 1 2 Excessively distressed if separated from familiar person.

23. 0 1 2 Fears particular things or situations, eg. the dark or insects.
Please describe:______________________________________________

24. 0 1 2 Facial twitches or grimaces.

25. 0 1 2 Flicks, taps, twirls objects repeatedly.

26. 0 1 2 Fussy eater or has food fads.

27. 0 1 2 Gorges food. Will do anything to get food, eg. takes food out of bins or steals food.

28. 0 1 2 Gets obsessed with an idea or activity.
Please describe:______________________________________________

29. 0 1 2 Grinds teeth.

30. 0 1 2 Has nightmares, night terrors or walks in sleep.

31. 0 1 2 Has temper tantrums, eg. stamps feet, slams doors.

32. 0 1 2 Hides things.

33. 0 1 2 Hits self or bites self.

34. 0 1 2 Hums, whines, grunts, squeals, or makes other non-speech noises.

35. 0 1 2 Impatient.

36. 0 1 2 Inappropriate sexual activity with another.

37. 0 1 2 Impulsive, acts before thinking.

38. 0 1 2 Irritable.

39. 0 1 2 Jealous.

40. 0 1 2 Kicks, hits others.

41. 0 1 2 Lacks self-confidence, poor self-esteem.

42. 0 1 2 Laughs or giggles for no obvious reason.

43. 0 1 2 Lights fires.

44. 0 1 2 Likes to hold or play with an unusual object, eg. string, twigs; overly fascinated with something, eg. water.
Please describe:______________________________________________

45. 0 1 2 Loss of appetite.

46. 0 1 2 Masturbates or exposes self in public.

**0 = not true as far as you know  1 = somewhat or sometimes true  2 = very true or often true**

| | **Please circle** | | | |
|---|---|---|---|---|
| 47. | **0** | **1** | **2** | Mood changes rapidly for no apparent reason. |
| 48. | **0** | **1** | **2** | Moves slowly, underactive, does little, eg. only sits and watches others. |
| 49. | **0** | **1** | **2** | Noisy or boisterous. |
| 50. | **0** | **1** | **2** | Overactive, restless, unable to sit still. |
| 51. | **0** | **1** | **2** | Overaffectionate. |
| 52. | **0** | **1** | **2** | Overbreathes, vomits, has headaches or complains of being sick for no physical reason. |
| 53. | **0** | **1** | **2** | Overly attention-seeking. |
| 54. | **0** | **1** | **2** | Overly interested in looking at, listening to or dismantling mechanical things, eg. lawnmower, vacuum cleaner. |
| 55. | **0** | **1** | **2** | Poor sense of danger. |
| 56. | **0** | **1** | **2** | Prefers the company of adults or younger children. Doesn't mix with his/her own age group. |
| 57. | **0** | **1** | **2** | Prefers to do things on his/her own. Tends to be a loner. |
| 58. | **0** | **1** | **2** | Preoccupied with only one or two particular interests.<br>Please describe:_______________________________________ |
| 59. | **0** | **1** | **2** | Refuses to go to school, activity centre or workplace. |
| 60. | **0** | **1** | **2** | Repeated movements of hands, body, head or feet, eg. handflapping or rocking. |
| 61. | **0** | **1** | **2** | Resists being cuddled, touched or held. |
| 62. | **0** | **1** | **2** | Repeats back what others say like an echo. |
| 63. | **0** | **1** | **2** | Repeats the same word or phrase over and over. |
| 64. | **0** | **1** | **2** | Smells, tastes, or licks objects. |
| 65. | **0** | **1** | **2** | Scratches or picks his/her skin. |
| 66. | **0** | **1** | **2** | Screams a lot. |
| 67. | **0** | **1** | **2** | Sleeps too little. Disrupted sleep. |
| 68. | **0** | **1** | **2** | Stares at lights or spinning objects. |
| 69. | **0** | **1** | **2** | Sleeps too much. |
| 70. | **0** | **1** | **2** | Soils outside toilet though toilet trained. Smears or plays with faeces. |
| 71. | **0** | **1** | **2** | Speaks in whispers, high pitched voice, or other unusual tone or rhythm. |
| 72. | **0** | **1** | **2** | Switches lights on and off, pours water over and over; or similar repetitive activity.<br>Please describe:_______________________________________ |
| 73. | **0** | **1** | **2** | Steals. |
| 74. | **0** | **1** | **2** | Stubborn, disobedient or uncooperative. |
| 75. | **0** | **1** | **2** | Shy. |
| 76. | **0** | **1** | **2** | Strips off clothes or throws away clothes. |
| 77. | **0** | **1** | **2** | Says he/she can do things that he/she is not capable of. |
| 78. | **0** | **1** | **2** | Stands too close to others. |
| 79. | **0** | **1** | **2** | Sees, hears, something which isn't there. Hallucinations.<br>Please describe:_______________________________________ |

**0 = not true as far as you know     1 = somewhat or sometimes true     2 = very true or often true**

**Please circle**

| | | | | |
|---|---|---|---|---|
| 80. | **0** | **1** | **2** | Talks about suicide. |
| 81. | **0** | **1** | **2** | Talks too much or too fast. |
| 82. | **0** | **1** | **2** | Talks to self or imaginary people or objects. |
| 83. | **0** | **1** | **2** | Tells lies. |
| 84. | **0** | **1** | **2** | Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow. |
| 85. | **0** | **1** | **2** | Tense, anxious, worried. |
| 86. | **0** | **1** | **2** | Throws or breaks objects. |
| 87. | **0** | **1** | **2** | Tries to manipulate or provoke others. |
| 88. | **0** | **1** | **2** | Underreacts to pain. |
| 89. | **0** | **1** | **2** | Unrealistically happy or elated. |
| 90. | **0** | **1** | **2** | Unusual body movements, posture, or way of walking.<br>Please describe:______________________________________________ |
| 91. | **0** | **1** | **2** | Upset and distressed over small changes in routine or environment.<br>Please describe:______________________________________________ |
| 92. | **0** | **1** | **2** | Urinates outside toilet, although toilet trained. |
| 93. | **0** | **1** | **2** | Very bossy. |
| 94. | **0** | **1** | **2** | Wanders aimlessly. |
| 95. | **0** | **1** | **2** | Whines and complains a lot. |
| 96. | **0** | **1** | **2** | Makes repetitive mouth and/or tongue movements, eg. grinds teeth or smacks lips.<br>Please describe:______________________________________________ |
| 97. | **0** | **1** | **2** | Insists on things about the house staying the same, eg. furniture in the same place |
| 98. | **0** | **1** | **2** | Insists on household and/or personal items being kept or stored in the same way, eg. ornaments or toys being kept in the same places or positions |
| 99. | **0** | **1** | **2** | Insists on using the same objects or items, eg. the same chair, plate, or bed linen |
| 100. | **0** | **1** | **2** | Insists on wearing the same clothes or refuses to wear new clothes |
| 101. | **0** | **1** | **2** | Insists on moving or travelling by the same route, eg. when walking or driving |
| | | | | Please write in any problems your child has that were not listed above: |
| 102. | **0** | **1** | **2** | ____________________________________________________________ |
| 103. | **0** | **1** | **2** | ____________________________________________________________ |
| 104. | **0** | **1** | **2** | ____________________________________________________________ |
| 105. | **0** | **1** | **2** | Overall, do you feel that your child has problems with feelings or behaviour, in addition to problems with development? If not, please circle the **0**. If so, but they're minor, please circle the **1**. If they're major problems, please circle the **2**. |

**Please feel free to make any further comments about your child's emotions, behaviour or personality.**

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

*Acknowledgement: Einfeld & Tonge, 1993.*

# Section 16: Current Measurements

*We are interested to know about the growth of children and young adults with Down syndrome, as well as any difficulties experienced in maintaining a healthy weight.*

1. **Please provide your child's current height.**

   ____________ cm or ____________ feet ____________ inches

   Date on which the measurement was made ___/___/___

2. **Please provide your child's current weight.**

   ____________ kg or ____________ pounds ____________ ounces

   Date on which the measurement was made ___/___/___

3. **Has your child experienced any difficulties maintaining a healthy weight?**

   ☐ No
   ☐ Yes - please comment on why you think there have been problems with maintaining a healthy weight (eg., poor diet, lack of exercise):

   ____________________________________________
   ____________________________________________
   ____________________________________________
   ____________________________________________
   ____________________________________________

# Section 1: Informal Assistance Needs

*Listed below are 12 different types of assistance which people sometimes find helpful. These questions ask you to indicate how much you would like help in these areas.*

Please circle the response that best describes your needs. Please answer all questions.

| **To what extent do you feel a need for any of the following types of help or assistance?** | **Never** | **Once in a while** | **Sometimes** | **Often** | **Quite often** |
|---|---|---|---|---|---|
| 1. Someone to talk to about things that worry you | 1 | 2 | 3 | 4 | 5 |
| 2. Someone to help take care of your child | 1 | 2 | 3 | 4 | 5 |
| 3. Someone to talk to when you have questions about raising your child | 1 | 2 | 3 | 4 | 5 |
| 4. Someone who loans you money when you need it | 1 | 2 | 3 | 4 | 5 |
| 5. Someone to encourage or keep you going when things seem hard | 1 | 2 | 3 | 4 | 5 |
| 6. Someone who accepts your child regardless of how s/he acts | 1 | 2 | 3 | 4 | 5 |
| 7. Someone to help with household chores | 1 | 2 | 3 | 4 | 5 |
| 8. Someone to relax or joke with | 1 | 2 | 3 | 4 | 5 |
| 9. Someone to do things with your child | 1 | 2 | 3 | 4 | 5 |
| 10. Someone to provide you or your child with transportation | 1 | 2 | 3 | 4 | 5 |
| 11. Someone to deal with agencies or individuals when you cannot | 1 | 2 | 3 | 4 | 5 |
| 12. Someone who tells you about services for your child or family | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Dunst and Trivette, 1988.*

**The following question relates to the availability of support and assistance in your NEIGHBOURHOOD.**

**13. Do you know any of your neighbours well enough to do any of the following?**
Please tick yes or no for all statements.

| | **Yes** | **No** |
|---|---|---|
| have a child minded for an hour in an emergency? | ☐ | ☐ |
| have a child minded regularly? | ☐ | ☐ |
| borrow $5 until you go to the bank? | ☐ | ☐ |
| borrow something else? | ☐ | ☐ |
| water the garden for you if you are away? | ☐ | ☐ |
| feed your pets if you are away? | ☐ | ☐ |
| have a talk with you if you are feeling down? | ☐ | ☐ |
| get small items of shopping if you are ill? | ☐ | ☐ |
| keep an eye on your home if you go away? | ☐ | ☐ |
| I live in area where there are no neighbours nearby | ☐ | ☐ |
| I have recently moved house | ☐ | ☐ |

*Acknowledgement: Zubrick, Williams, Silburn and Vimpani, 2000.*

# Section 2: Availability Of Time

*Caring for a child with Down syndrome may or may not place added demands on a parent's time. The following items ask whether you feel you have enough time to meet the requirements of the family as a whole and also to meet your own individual requirements.*

For each item, please circle the response that best describes how well the requirement is met on a consistent basis in your family (that is, month in and month out).

| To what extent are the following time resources adequate for you | Does not apply | Not at all adequate | Seldom adequate | Sometimes adequate | Usually adequate | Almost always adequate |
|---|---|---|---|---|---|---|
| 1. Time to get enough sleep/rest | NA | 1 | 2 | 3 | 4 | 5 |
| 2. Time to be by yourself | NA | 1 | 2 | 3 | 4 | 5 |
| 3. Time for family to be together | NA | 1 | 2 | 3 | 4 | 5 |
| 4. Time to be with child(ren) | NA | 1 | 2 | 3 | 4 | 5 |
| 5. Time to be with your spouse or partner | NA | 1 | 2 | 3 | 4 | 5 |
| 6. Time to be with close friend(s) | NA | 1 | 2 | 3 | 4 | 5 |
| 7. Time to socialise | NA | 1 | 2 | 3 | 4 | 5 |
| 8. Time to keep in shape and look nice | NA | 1 | 2 | 3 | 4 | 5 |
| 9. Time and money for travel/vacation | NA | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Dunst et al, 1988.*

# Section 3: Agreement With Your Partner

*We are interested in the extent of agreement between you and your partner.*
*"Partner" is the person with whom you have the most significant relationship.*
*For example, partner could be a spouse, girl/boyfriend, parent or sibling.*

1. **Please indicate the approximate extent of agreement or disagreement between you and your partner for each of the following three items.**
**Please circle the number which best fits your answer.**

| | Always agree | Almost always agree | Occasionally disagree | Frequently disagree | Almost always disagree | Always disagree |
|---|---|---|---|---|---|---|
| 1. Philosophy of life | 5 | 4 | 3 | 2 | 1 | 0 |
| 2. Aims, goals and things believed to be important | 5 | 4 | 3 | 2 | 1 | 0 |
| 3. Amount of time spent together | 5 | 4 | 3 | 2 | 1 | 0 |

2. **How often would you say the following events occur between you and your partner?**

| | Never | Less than once a month | Once or twice a month | Once or twice a week | Once a day | More often |
|---|---|---|---|---|---|---|
| 4. Have a stimulating conversation | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. Calmly discuss something | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. Work together on a project | 0 | 1 | 2 | 3 | 4 | 5 |

3. **The dots on the following line represent different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships.**
**Please circle <u>the dot</u> which best describes the degree of happiness, all things considered, of your relationship.**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| ● | ● | ● | ● | ● | ● | ● |
| Extremely unhappy | Fairly unhappy | A little unhappy | Happy | Very happy | Extremely happy | Perfect |

*Acknowledgement: Sharpley and Rogers, 1984.*

# Section 4: Family and Down syndrome

*We are interested in finding out about how having a child with Down syndrome affects you and other family members.*

1. **Apart from your child with Down syndrome do you have any other children (including foster and/or adopted children)?**

   ☐ No, please go to question 4
   ☐ Yes, please provide us with some information which may be helpful to Down syndrome research:

| Relationship to child with Down syndrome | Date of birth | Gender | Serious medical conditions or disabilities? (Please list) | Lives with child with Down syndrome? |
|---|---|---|---|---|
| **Example answer** | | | | |
| Sister | 20.10.93 | F | None | ☑ Yes ☐ No |
| **Your answer** | | | | |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |

2. **Do you think there have been benefits to your other children because they have a sibling with Down syndrome?**

   ☐ No
   ☐ Yes, please describe the benefits in the following space:

3. **Do you think there have been disadvantages to your other children because they have a sibling with Down syndrome?**

   ☐ No
   ☐ Yes, please describe the disadvantages in the following space:

4. **Please describe the impact (if any) of having a child with Down syndrome on family recreational activities.**

5. **Please describe the impact (if any) of Down syndrome on family holidays.**

6. **Please feel free to write any comments about other ways in which having a child with Down syndrome has affected your family.**

# Section 5: Family Communication

*The following questions ask about aspects of communication between members of your family.*
*We would like to know whether there are changes in the dynamics of families who care for a child with a disability.*

Please circle the response that best suits your answer.
"Agree" means that while you do not "strongly agree" with the statement, you would tend to agree more often than disagree.
"Disagree" means that you would tend to disagree more often than you would agree with the statement.

| | Strongly agree | Agree | Disagree | Strongly disagree |
|---|---|---|---|---|
| 1. Planning family activities is difficult because we misunderstand each other | SA | A | D | SD |
| 2. In times of crisis we can turn to each other for support | SA | A | D | SD |
| 3. We cannot talk to each other about sadness we feel | SA | A | D | SD |
| 4. Individuals (in the family) are accepted for what they are | SA | A | D | SD |
| 5. We avoid discussing our fears and concerns | SA | A | D | SD |
| 6. We express feelings to each other | SA | A | D | SD |
| 7. There are lots of bad feelings in our family | SA | A | D | SD |
| 8. We feel accepted for what we are | SA | A | D | SD |
| 9. Making decisions is a problem in our family | SA | A | D | SD |
| 10. We are able to make decisions about how to solve problems | SA | A | D | SD |
| 11. We don't get on well together | SA | A | D | SD |
| 12. We confide in each other | SA | A | D | SD |

*Acknowledgement: Epstein, Baldwin and Bishop, 1983.*

# Section 6: Self Assessment of Mood

*Whilst many things may contribute to the ups and downs in one's life, we would like to know whether your every day moods and feelings are influenced by caring for a child with Down syndrome.*

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

**The rating scale is as follows :**
0 Did not apply to me at all.
1 Applied to me to some degree, or some of the time.
2 Applied to me a considerable degree, or a good part of the time.
3 Applied to me very much, or most of the time.

---

1. I found it hard to wind down. 0 1 2 3
2. I was aware of dryness in my mouth. 0 1 2 3
3. I couldn't seem to experience any positive feelings at all. 0 1 2 3
4. I experienced breathing difficulty (eg. excessively rapid breathing, breathlessness in the absence of physical exertion). 0 1 2 3
5. I found it difficult to work up the initiative to do things. 0 1 2 3
6. I tended to over-react to situations. 0 1 2 3
7. I experienced trembling (eg. in the hands). 0 1 2 3
8. I felt that I was using a lot of nervous energy. 0 1 2 3
9. I was worried about situations in which I might panic and make a fool of myself. 0 1 2 3
10. I felt that I had nothing to look forward to. 0 1 2 3
11. I found myself getting agitated. 0 1 2 3
12. I found it difficult to relax. 0 1 2 3
13. I felt down-hearted and blue. 0 1 2 3
14. I was intolerant of anything that kept me from getting on with what I was doing. 0 1 2 3
15. I felt I was close to panic. 0 1 2 3
16. I was unable to become enthusiastic about anything. 0 1 2 3
17. I felt that I wasn't worth much as a person. 0 1 2 3
18. I felt I was rather touchy. 0 1 2 3
19. I was aware of the action of my heart in the absence of physical exertion (eg. sense of heart rate increase, heart missing a beat). 0 1 2 3
20. I felt scared without any good reason. 0 1 2 3
21. I felt that life was meaningless. 0 1 2 3

---

*Acknowledgement: Lovibond and Lovibond, 1993.*

# Section 7: Self Assessment Of Personal Health

*The state of one's health may be of extra importance for a parent caring for a child with Down syndrome.*
*The following questions ask for your views about your health.*

Answer every question by marking the circle that best fits your answer.
If you are unsure about how to answer a question, please give the best answer you can.

| | Excellent | Very good | Good | Fair | Poor |
|---|---|---|---|---|---|
| 1. In general, would you say your health is: | ○ | ○ | ○ | ○ | ○ |

**The following questions are about activities you might do during a typical day.**
**Does your health *now* limit you in these activities? If so, how much?**

| | Yes, limited a lot | Yes, limited a little | No, not limited at all |
|---|---|---|---|
| 2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf: | ○ | ○ | ○ |
| 3. Climbing several flights of stairs: | ○ | ○ | ○ |

**During the past *4 weeks*, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| 4. Accomplished less than you would like: | ○ | ○ | ○ | ○ | ○ |
| 5. Were limited in the kind of work or other activities: | ○ | ○ | ○ | ○ | ○ |

**During the past *4 weeks*, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| 6. Accomplished less than you would like: | ○ | ○ | ○ | ○ | ○ |
| 7. Didn't do work or other activities as carefully as usual: | ○ | ○ | ○ | ○ | ○ |

**8. During the past *4 weeks*, how much did pain interfere with your normal work (including both work outside the home and housework)?**

| Not at all | A little bit | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ |

---

**These questions are about how you feel and how things have been with you during the past *4 weeks*. For each question, please give the one answer that comes closest to the way you have been feeling.**

How much of the time during the past 4 weeks.....

|  | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| **9. Have you felt calm and peaceful?** | ○ | ○ | ○ | ○ | ○ |
| **10. Did you have a lot of energy?** | ○ | ○ | ○ | ○ | ○ |
| **11. Have you felt downhearted and blue?** | ○ | ○ | ○ | ○ | ○ |

---

**12. During the past *4 weeks*, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**

| All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ |

---

**13. Please discuss the impact that having a child with Down syndrome has had on the health of the family. This may be mental, physical or any other aspect of health.**

*Acknowledgement: Ware, Kosinski and Keller, 1996.*

# Section 8: Family And Community Support

*Listed below are people and groups that are often helpful to members of a family raising a child with Down syndrome. The following questions ask you to indicate how helpful each source is to your family.*

Please circle the response that best describes how helpful the sources have been to your family during the past **3 to 6 months**. If a source of help has not been available to your family during this period of time, circle the NA (Not applicable) response.

| How helpful has each of the following been to you in terms of raising your child with Down syndrome? | Not applicable | Not at all helpful | Sometimes helpful | Generally helpful | Very helpful | Almost always adequate |
|---|---|---|---|---|---|---|
| 1. My parents | NA | 1 | 2 | 3 | 4 | 5 |
| 2. My spouse or partner's parents | NA | 1 | 2 | 3 | 4 | 5 |
| 3. My relatives | NA | 1 | 2 | 3 | 4 | 5 |
| 4. My spouse or partner's relatives | NA | 1 | 2 | 3 | 4 | 5 |
| 5. Spouse or partner | NA | 1 | 2 | 3 | 4 | 5 |
| 6. My friends | NA | 1 | 2 | 3 | 4 | 5 |
| 7. My spouse or partner's friends | NA | 1 | 2 | 3 | 4 | 5 |
| 8. My own children | NA | 1 | 2 | 3 | 4 | 5 |
| 9. Other parents | NA | 1 | 2 | 3 | 4 | 5 |
| 10. Co-workers | NA | 1 | 2 | 3 | 4 | 5 |
| 11. Parent groups | NA | 1 | 2 | 3 | 4 | 5 |
| 12. Social groups / clubs | NA | 1 | 2 | 3 | 4 | 5 |
| 13. Members of church or religious group / minister or leader | NA | 1 | 2 | 3 | 4 | 5 |
| 14. My family or child's physician | NA | 1 | 2 | 3 | 4 | 5 |
| 15. Early childhood intervention program | NA | 1 | 2 | 3 | 4 | 5 |
| 16. Play group / school / day-care centre | NA | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Dunst, Jenkins and Trivette, 1988.*

# Section 9: Spirituality

*We are interested in the support you might receive from religious organisations as well as the personal comfort you might gain from your spiritual beliefs.*

Please circle the response that best applies to you. Even if you are not religious or do not attend church, please read each statement and circle 0 for"not applicable" if it does not apply to you.

| **These questions relate to ORGANISED RELIGION:** | not applicable | strongly disagree | disagree | neither agree or disagree | agree | strongly agree |
|---|---|---|---|---|---|---|
| 1. My clergyman/minister was helpful to me when my child with Down syndrome was born | 0 | 1 | 2 | 3 | 4 | 5 |
| 2. I am satisfied with the availability of religious education available for my child | 0 | 1 | 2 | 3 | 4 | 5 |
| 3. I am more active in our church since my child with Down syndrome was born | 0 | 1 | 2 | 3 | 4 | 5 |
| 4. If I had problems with my child I would seek help from our church | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. The church has been more supportive of me than other agencies | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. Most of my social activities involve members of my church/parish community | 0 | 1 | 2 | 3 | 4 | 5 |

| **These questions relate to your PERSONAL BELIEFS about religion or spirituality:** | not applicable | strongly disagree | disagree | neither agree or disagree | agree | strongly agree |
|---|---|---|---|---|---|---|
| 7. My personal beliefs have helped me to understand and accept my child with Down syndrome | 0 | 1 | 2 | 3 | 4 | 5 |
| 8. I am satisfied that our personal beliefs are fulfilling our family's spiritual needs | 0 | 1 | 2 | 3 | 4 | 5 |
| 9. Having a child with Down syndrome has brought me closer to God and my religion | 0 | 1 | 2 | 3 | 4 | 5 |
| 10. I seek comfort through prayer | 0 | 1 | 2 | 3 | 4 | 5 |
| 11. My personal beliefs continue to be a source of comfort in coping with our child with Down syndrome | 0 | 1 | 2 | 3 | 4 | 5 |
| 12. My personal beliefs are a source of personal and family strength to me in everyday life | 0 | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Fewell, 1986.*

# Questionnaire Feedback

1. **Did you find any of the questions confusing or difficult to answer?**

☐ No - please go to question 2
☐ Yes - please describe which questions in the space below:

2. **Did you find any of the questions upsetting?**

☐ No - please go to question 3
☐ Yes - please describe which questions in the space below:

3. **Are there any other questions or topics you think we should have included?**

☐ No
☐ Yes - please make any suggestions in the space below:

4. **How long did it take you to complete the questionnaire?** ____________________

**If you have any further comments about this questionnaire, this research or anything else that you would like to tell us about, please make them in the space below:**

________________________________________________________

________________________________________________________

________________________________________________________

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________________________________________________________

**Thank you so much for taking the time to complete this questionnaire.**
**We appreciate your contribution to Down syndrome research.**

Please return this questionnaire and the consent form
in the reply paid envelope provided to:
Dr Helen Leonard
Down Syndrome Study
Telethon Institute for Child Health Research
PO Box 855
WEST PERTH WA 6872

Appendix C: 2009 Down syndrome 'NOW' questionnaire

# DOWN SYNDROME NOW

NEEDS OPINIONS WISHES
STUDY 2009

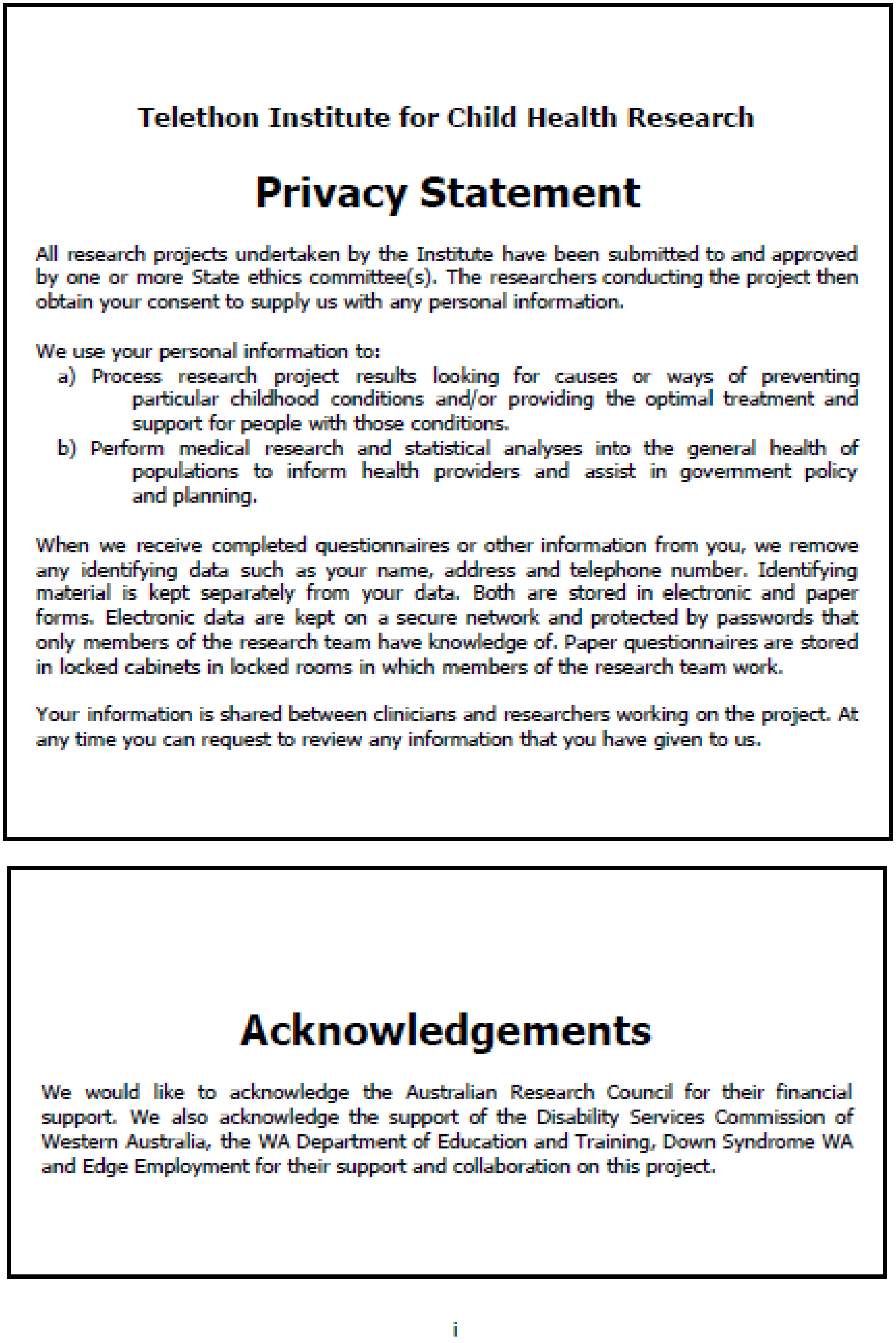
## TRANSITION FROM SCHOOL TO ADULTHOOD

## A questionnaire for parents

Thank you for taking part in this study.

If you have **any** queries about this questionnaire or the study in general, **please** do not hesitate to contact:

**Dr Helen Leonard**
**(Medical Director)**
Phone: 08 9489 7790
Fax: 08 9489 7700
Mobile: 0419 956 946
Email: hleonard@ichr.uwa.edu.au



## Telethon Institute for Child Health Research

# Privacy Statement

All research projects undertaken by the Institute have been submitted to and approved by one or more State ethics committee(s). The researchers conducting the project then obtain your consent to supply us with any personal information.

We use your personal information to:

a) Process research project results looking for causes or ways of preventing particular childhood conditions and/or providing the optimal treatment and support for people with those conditions.
b) Perform medical research and statistical analyses into the general health of populations to inform health providers and assist in government policy and planning.

When we receive completed questionnaires or other information from you, we remove any identifying data such as your name, address and telephone number. Identifying material is kept separately from your data. Both are stored in electronic and paper forms. Electronic data are kept on a secure network and protected by passwords that only members of the research team have knowledge of. Paper questionnaires are stored in locked cabinets in locked rooms in which members of the research team work.

Your information is shared between clinicians and researchers working on the project. At any time you can request to review any information that you have given to us.

# Acknowledgements

We would like to acknowledge the Australian Research Council for their financial support. We also acknowledge the support of the Disability Services Commission of Western Australia, the WA Department of Education and Training, Down Syndrome WA and Edge Employment for their support and collaboration on this project.

# TABLE OF CONTENTS

**PART 1 Sections:**

**PART 2 Sections:**

# PART 1 - YOUR SON/ DAUGHTER : INSTRUCTIONS

The questions in the first part of this booklet relate to your son or daughter with Down syndrome. The information you provide will help explain what happens to individuals with Down syndrome and their families over time and why the outcomes may differ as the young people move from adolescence to adulthood.

You will find that not all questions will apply to your child, and so you will not have to respond to every question or complete every section. Please note that you are not required to fill out the entire questionnaire in one sitting - you may wish to complete it over a few separate occasions.

Even though your young adult may not be living at home with you, we would still like you to fill out the questionnaire as your perspective on the issues raised is important. Parents and other people involved in providing care and support to people with Down syndrome have advised and guided us in the development of the questionnaire.

If you participated in the Down syndrome study in 2004, we greatly appreciate you taking the time again to complete this questionnaire which is particularly related to issues around transition from school to adulthood. We are again asking questions on your son/ daughter's health and use of services, family resources and your son/ daughter's level of functioning as this may have changed over the last 5 years and these are factors which may affect outcomes.

The questions ask you to either mark a box, fill in a table or write in a space. We have provided you with a "Glossary of Terms" at the end to assist you with any words or phrases you may not have seen before. If there are any questions which seem unclear or are difficult to understand, please do not hesitate to contact Dr Helen Leonard (details are on the cover page of this booklet), who will be happy to help you.

**We are very appreciative of the time that you are giving to complete this questionnaire. Your contribution to this research will be extremely valuable in identifying the major issues currently facing young adults with Down syndrome and their families. We hope this research will lead to strategies and policies that will improve future outcomes as young people with Down syndrome transition from school to adulthood.**

# Section 1: Parent Information

*These first questions are to collect some background information about the parents of the young adult with Down syndrome.*

**1. Please indicate your relationship to the young adult who has Down syndrome.**
***Note: If more than one person is filling out the questionnaire, please tick all boxes that apply.***

☐ Natural mother
☐ Natural father
☐ Foster mother
☐ Foster father
☐ Adoptive mother
☐ Adoptive father
☐ Stepmother
☐ Stepfather
☐ Other (please specify)__________________________

**Questions 2 - 6 are about the MOTHER of the young adult with Down syndrome (including the stepmother, foster or adoptive mother if she provides most of the child's care).**

**2. In which country was the child's mother born?** __________________________________________

**3. What is her first language?** ____________________________________________________________

**4. What is her date of birth?** __________/______________/______________ **(Day/Month/Year)**

**5. What is the highest qualification that she has completed?**

☐ Primary school
☐ Some high school
☐ Completed high school (Year 12 or equivalent)
☐ Trade or technical qualification (Certificate level)
☐ Advanced diploma
☐ Bachelor degree
☐ Graduate diploma or certificate
☐ Postgraduate degree (Masters or PhD)

**6. Which of the following best describes her current work status?** ***(Please tick all that apply)***

☐ Not working due to her child's disability
☐ Full time homemaker
☐ Not working for other reasons
☐ Looking for work outside the home
☐ Working full time (either outside the home or at a home-based business)
☐ Working part-time

**Please also indicate, if applicable :**

**Has chosen self employment due to her child's disability** ☐ **Yes** ☐ **No**

Please provide the following information for all jobs currently held:

Job title: ________________________________________ Hours worked per week:_______

Main tasks: ______________________________________________________________

Job title: ________________________________________ Hours worked per week:_______

Main tasks: ______________________________________________________________

**6a If your son/ daughter has left school, has THE MOTHER'S work situation changed as a result of your son/ daughter leaving school** **Yes** ☐ **No** ☐

Please Comment__________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

**Questions 7 - 11 are about the FATHER of the child with Down syndrome (including the stepfather, foster or adoptive father if he provides most of the child's care).**

**7. In which country was the child's father born?** ______________________________

**8. What is his first language?** ______________________________

**9. What is his date of birth?** ________/__________/__________ **(Day/Month/Year)**

**10. What is the highest qualification that he has completed?**

☐ Primary school
☐ Some high school
☐ Completed high school (Year 12 or equivalent)
☐ Trade or technical qualification (Certificate level)
☐ Advanced diploma
☐ Bachelor degree
☐ Graduate diploma or certificate
☐ Postgraduate degree (Masters or PhD)

**11. Which of the following best describes his current work status?** ***(Please tick all that apply)***

☐ Not working due to his child's disability
☐ Full time homemaker
☐ Working full time (either outside the home or at a home-based business)
☐ Working part-time
☐ Not working for other reasons
☐ Looking for work outside the home

**Please also indicate, if applicable :**

**Has chosen self employment due to his child's disability** ☐ **Yes** ☐ **No**

Please provide the following information for all jobs currently held:

Job title: ______________________________ Hours worked per week:______

Main tasks: ______________________________

Job title: ______________________________ Hours worked per week:______

Main tasks: ______________________________

**11a If your son/ daughter has left school, has THE FATHER'S work situation changed as a result of your son/daughter leaving school** ☐ **Yes** ☐ **No**

Please Comment______________________________

______________________________

**Questions 12 - 14 are about your child with Down syndrome**

**12. What is your child's date of birth?** ________/__________/__________ **(Day/Month/Year)**

**13. What is your child's gender?** ☐ Male ☐ Female

**14. Where was your child born?** Country______________________

State______________________

**14a Are you currently living in** ☐ Metropolitan area

☐ Country WA -
approximate distance from nearest main town________________

Part 1: S1-2

# SECTION 2: MEDICAL CONDITIONS

*This section asks about health and medical conditions as it is important to understand how these may affect what the young adult is able to do.*

1. **Has your son/ daughter EVER been diagnosed with a HEART condition such as VSD (ventricular septal defect), ASD (atrial septal defect), Tetralogy of Fallot or another heart condition?**

☐ No - **please go to Question 2.**
☐ Yes - please fill out sections a) & b) below

**a) Please indicate in the table below, the name or description of the heart condition(s), whether surgery was performed, and if so, the date the surgery was performed OR the child's age at surgery.**

| Name or description of heart condition | Type of surgery for the condition, if any | Date of OR age at surgery |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**b) Does your son/ daughter have any current problems or receive continued treatment (including medication) because of the heart condition(s)?**

☐ No - **please go to Question 2.**
☐ Yes - please complete the table below

| Current heart problem | Treatment If medication, include name, dosage and frequency |
|---|---|
| | |
| | |
| | |
| | |

2. **Does your young adult have any current problems or receive continued treatment (including medication) because of any BOWEL or GASTROINTESTINAL condition(s)? (such as constipation, reflux)**

☐ No - **please go to Question 3.**
☐ Yes - please complete the table below

| Current bowel or gastrointestinal problem | Treatment If medication, include name, dosage and frequency |
|---|---|
| | |
| | |
| | |
| | |

**3. Does your son/ daughter have any current problems or receive continued treatment (including medication) because of a HEARING or EAR condition(s) such as glue ear, a burst (perforated) ear drum, deafness or another hearing or ear condition?**

☐ No - **please go to Question 4.**

☐ Yes - please complete the table below

| **Current ear problem** | **Treatment**<br>**If medication, include name, dosage and frequency** |
|---|---|
| | |
| | |
| | |
| | |

**4. Does your son/ daughter have any current problems or receive continued treatment (including glasses) because of an EYE condition(s) such as short sightedness, squint, cataracts or another eye condition?**

☐ No - **please go to Question 5.**

☐ Yes - please complete the table below

| **Current eye problem** | **Treatment**<br>**If medication, include name, dosage and frequency** |
|---|---|
| | |
| | |
| | |
| | |

**5. Does your son/ daughter have any current problems or receive continued treatment (including medication) because of a THYROID condition(s) such as an underactive thyroid (hypothyroidism) or an overactive thyroid (hyperthyroidism)?**

☐ No - **please go to Question 6.**

☐ Yes - please complete the table below

| **Current thyroid problem** | **Treatment**<br>**If medication, include name, dosage and frequency** |
|---|---|
| | |
| | |
| | |
| | |

**6. Does your son/ daughter have any current problems or receive continued treatment (including medication, orthotics or braces) because of a MUSCLE and/or BONE (orthopaedic) condition, such as atlantoaxial instability, scoliosis, flat-footedness, or hamstring problems?**

☐ No - **please go to Question 7.**
☐ Yes - please complete the table below

| **Current muscle or bone problem** | **Treatment**<br>**If medication, include name, dosage and frequency** |
|---|---|
| | |
| | |
| | |
| | |

**a) Has your son/ daughter ever had an X-ray of the neck?**

☐ No - **please go to Question 7.**
☐ Yes - Was any problem found? ☐ No
☐ Yes - Please describe what was found:

---

**7. Does your son/ daughter have any current problems or receive continued treatment (including medication) for any RESPIRATORY conditions such as asthma, bronchitis, pneumonia, sleep apnoea or fluid in the lungs?**

☐ No - **please go to Question 8.**
☐ Yes - please complete the table below

| **Current respiratory problem** | **Treatment**<br>**If medication, include name, dosage and frequency** |
|---|---|
| | |
| | |
| | |
| | |

**8. Does your son/ daughter have any current problems or receive continued treatment (including medication) because of any OTHER significant health conditions not already mentioned (eg., epilepsy, diabetes, leukaemia, eczema)?**

☐ No
☐ Yes - please complete the table below

| **Current problem** | **Treatment**<br>**If medication, include name, dosage and frequency** |
|---|---|
| | |
| | |
| | |

# SECTION 3: MEDICAL CARE, SERVICES AND ILLNESS IN 2009

*It is important to know the illnesses experienced by young adults with Down syndrome as this may impact on how much they are able to work. It is also important to know whether you feel your son/daughter's medical care needs are being met.*

**1. Please complete the following question relating to the medical or other health care that your son/ daughter has received IN THE LAST 12 MONTHS which DID NOT INVOLVE ADMISSION TO HOSPITAL.**

Please note this table does NOT include visits to allied health therapists (eg., physiotherapists) or alternative therapists (eg., chiropractor, naturopaths) - we will ask you about those later.

| Type of practitioner | Number of visits in last 12 months |
|---|---|
| GP standard visit | |
| GP long visit | |
| Eye specialist | |
| Ear, nose & throat specialist | |
| Podiatrist | |
| Dentist | |
| Orthodontist | |
| Audiologist | |
| Cardiologist | |
| Other | |

**2. Has your son/ daughter had any medical care that involved <u>day admissions or overnight stays</u> in hospital IN THE LAST 12 MONTHS? If your child was admitted for a specific procedure, please write the name of the procedure.**

☐ No - **please go to Question 3.**
☐ Yes - please describe the admission(s) in the following table

| Hospital stay | Reason for admission |
|---|---|
| 1 | |
| 2 | |
| 3 | |
| 4 | |
| 5 | |

**Please list any major investigations or procedures s/he had during any of the admissions:**

**3.** **IN THE LAST 12 MONTHS has your son/daughter had any of the conditions listed in the following table?** For each condition that s/he has had, please also indicate the number of episodes

| Name of condition | Has your child had the condition in the last 12 months | | Number episodes |
|---|---|---|---|
| Cold or flu | ☐ Yes | ☐ No | ☐ |
| Tonsilitis | ☐ Yes | ☐ No | ☐ |
| Pneumonia | ☐ Yes | ☐ No | ☐ |
| Bronchitis | ☐ Yes | ☐ No | ☐ |
| Asthma | ☐ Yes | ☐ No | ☐ |
| Ear infection | ☐ Yes | ☐ No | ☐ |
| Urinary tract infection | ☐ Yes | ☐ No | ☐ |
| Other, please describe | ☐ Yes | ☐ No | ☐ |

**4.** **Please rate to what extent the medical care needs of your son/ daughter have been met IN THE LAST 12 MONTHS?**

☐ To a very great extent
☐ To a great extent
☐ To a fairly great extent
☐ To a moderate extent
☐ To a small extent
☐ To a very small extent
☐ Not at all
☐ Does not apply

**Please add any comments here:**

**5.** **IF YOUR SON /DAUGHTER HAS LEFT SCHOOL, has there been any change in the extent of overall medical care received since leaving school?**

☐ Much better care
☐ A little better care
☐ Unchanged
☐ A little worse care
☐ Much worse care

**Please add any comments here:**

6. **Please list in the table below all of the allied health therapists that your SON/DAUGHTER sees or has seen IN THE LAST 12 MONTHS .**
Typical practitioners may include: physiotherapist, occupational therapist, speech therapist

| Type of practitioner | Number of visits in last 12 months |
|---|---|
| | |
| | |
| | |
| | |
| | |

7. **Please list in the table below all of the alternative or complementary practitioners that your son/ daughter sees or has seen IN THE LAST 12 MONTHS .**
Typical practitioners may include: Chinese medicine or acupuncturists, chiropractors, herbalists, massage therapists, naturopaths, osteopaths, reflexologists, etc.

| Type of practitioner | Number of visits in last 12 months |
|---|---|
| | |
| | |
| | |
| | |
| | |

8. **Please list below all of the REGULAR medications and supplements not previously listed that your son/ daughter is taking and the reason for taking it.**
These may be for the treatment of various conditions, such as pain or sleeping problems, or for the everyday health of your child. We would like you to include prescription and non-prescription medications, and vitamin, mineral and food supplements, as well as anything from alternative therapists.

| Name of medication | Reason for medication |
|---|---|
| | |
| | |
| | |
| | |
| | |

9. **Do you have any comments about the availability of medical care in your area? (Include comments on any CHANGES to the availability of medical care over the past few years)**

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

# SECTION 4: GENERAL DISABILITY SERVICES

*We would like to know about the assistance YOU may receive from people in order to help you with your son/ daughter's care and/or to make it easier for you to care for your son/ daughter.*

**1. People caring for a young person with Down syndrome may occasionally need 'time-out'. This could involve a variety of things such as someone coming to your house, your son/ daughter going into respite care for a weekend, going on a respite camp for a few days or parents taking a break away.**

☐ I HAVE NEVER requested respite care, **please go to Question 2.**
☐ I HAVE NEVER received any respite care, **please go to Question 2.**
☐ I HAVE received respite care, **please answer the following questions.**

**1a. Have you received any IN-HOME respite care for your son/ daughter in the LAST 12 MONTHS?**

☐ No, **please go to Question 1b.**
☐ Yes - How many times have you received respite, in the last 12 months?_______times.
How many hours of care do you usually receive each time?_________hours.
Which person(s), agency or organisations provide the care?

________________________________________

**Please feel free to comment about IN-HOME respite care and the availability in your area**

________________________________________

**1b. Has your child been in OVERNIGHT respite care outside the home in the LAST 12 MONTHS?**

☐ No, **please go to Question 1c.**
☐ Yes - How many nights has your child been in overnight respite care, in the last 12 months? ____________nights.

Where does your child go for respite care? (Please provide the name of the facility)

________________________________________

**Please feel free to comment about OVERNIGHT respite care and the availability in your area**

________________________________________

**1c. Have you received any other type of care to give you 'time-out' that has not already been mentioned above, in the LAST 12 MONTHS (eg., respite camps for parents)?**

☐ No, **please go to Question 1d.**
☐ Yes - please describe below:

________________________________________
________________________________________
________________________________________

**1d. Please feel free to make any comments about respite support.**

________________________________________
________________________________________

**2.** **As a result of your son /daughter having Down syndrome, have you received or used services from support groups or organisations in the LAST 12 MONTHS?**

☐ No - **please go to Question 4.**
☐ Yes - please complete the following table as well as Question 3

| Type of service | Name of support group/ organisation | Any comments about the service? |
|---|---|---|
| **Example answers** | | |
| Advocacy support | Down Syndrome WA | Supported me to attend a meeting |
| Workshop | Carers WA | |
| **Your answer** | | |
| | | |
| | | |
| | | |
| | | |

**3.** **Which of the above groups or organisations has been the most important source of support for you, and why?**

________________________________________
________________________________________
________________________________________
________________________________________

**4.** **Have you EVER contacted Down Syndrome WA for support or information?**

☐ No
☐ Yes - please comment on the ways in which Down Syndrome WA has or has not been a source of support or help for you:

________________________________________
________________________________________
________________________________________

**5.** **Are you currently a member of or involved in any parent or professional organisation for families of children with a disability?**

☐ No ☐ Yes : Name__________________________

**If yes, how involved are you?**

☐ Little/ none ☐ Some ☐ A great deal

**6.** **Do you have access to the internet?**

☐ No
☐ Yes: If so, do you use it for
☐ Online support
☐ Information
☐ Other __________________________________

Part 1: S4-2

# SECTION 5: RESOURCES & INCOME

*This section asks about family resources which may have an impact on your son/ daughter's experiences as they move into adulthood.*

**1. Does the person with Down syndrome have a health care card?** ☐ Yes ☐ No

**1a. Do you have private health insurance for your child with Down syndrome?**

☐ No- **please go to Question 2**

☐ Yes- please indicate what level of cover you have

☐ Hospital only ☐ Extras only ☐ Hospital and Extras ☐ Other

Please describe if other: ____________________

**1b. Did you decide to take out private health insurance because your son/daughter has Down syndrome?** ☐ Yes ☐ No

**If yes, what were the reasons for taking out private health insurance?**
***(Please tick all that apply)***

☐ I believe the family needs private health insurance because we have a child with Down syndrome
☐ I believe that the level of care will be better with private health insurance.
☐ I started cover so we don't have to be on waiting lists.
☐ I increased our level of cover so we receive benefits for more health services.
☐ Other

Please describe Other reason:________________________________________________:

**2. If you, your spouse/partner, or son/daughter are receiving any benefits or pensions, please write the NUMBER OF EACH that are received in the corresponding boxes below.**

| | | | |
|---|---|---|---|
| Unemployment allowance | ☐ | Parenting payment (partnered) | ☐ |
| Age pension | ☐ | Sickness allowance | ☐ |
| Disability support pension | ☐ | Special benefit | ☐ |
| Mobility allowance | ☐ | Carer allowance (formerly called the Child Disability Allowance for children under 16) | ☐ |
| Education allowance (Pensioner education supplement) | ☐ | | |
| Mature age allowance | ☐ | Carer payment (means tested) | ☐ |
| Department of Veteran Affairs | ☐ | Other:____________________ | |
| Parenting payment (single) | ☐ | Other:____________________ | |

**3. Which words best describe your family's money situation?** (Tick the box that best applies to you)

☐ We are spending more money than we get
☐ We have just enough money to get us through to the next pay day
☐ There's some money left over each week but we just spend it
☐ We can save a bit every now and again
☐ We can save a lot

**4. What do you estimate the combined gross parental income (before tax) was in the 2008/2009 financial year, not including benefits and pensions? (Please tick only one box)**

☐ Less than $18,199
☐ Between $18,200 and $33,799
☐ Between $33,800 and $41,599
☐ Between $41,600 and $51,999
☐ Between $52,000 and $72,799
☐ Between $72,800 and $88,399
☐ Between $88,400 and $129,999
☐ $130,000 and above
☐ I prefer not to answer this question

5. **How available is transport BY CAR (own car or provided by others) for your family?**
*(Please tick one box)*

☐ Not at all adequate
☐ Seldom adequate
☐ Sometimes adequate
☐ Usually adequate
☐ Almost always adequate
☐ Not applicable

6. **How accessible is PUBLIC transport (eg., buses, trains) for your family?**
*(Please tick one box)*

☐ Not at all adequate
☐ Seldom adequate
☐ Sometimes adequate
☐ Usually adequate
☐ Almost always adequate
☐ Not applicable

7. **Does YOUR SON/DAUGHTER with Down syndrome use public transport?**
*(Please tick one box)*

☐ Not at all
☐ Seldom
☐ Sometimes
☐ Usually
☐ Almost always
☐ Not applicable

8. **Do you have a Taxi Users Subsidy Scheme (TUSS) voucher book**

☐ No ☐ Yes

**How often do you use taxis under this scheme**

☐ Not at all
☐ Seldom
☐ Sometimes
☐ Usually
☐ Almost always
☐ Not applicable

9. **Please write any comments you may have about the impact of your available resources on your son/ daughter's transition experiences:**

______________________________________________________________

______________________________________________________________

# SECTION 6: SEXUALITY

*This section asks about the physical and emotional development of your son/ daughter as these issues may be relevant to how they cope in the work place.*

**1. Is there anything about your son/daughter's sexual development that you would consider to be unusual or different from what you would expect for his/her age?**

☐ No
☐ Yes - please describe in the following space:

**2. Is there anything about your young adult's social and emotional development or behaviour that you would consider to be unusual or different from what you would expect for his/her age, or that you need/needed to handle in a different way because your son/ daughter has Down syndrome?**

☐ No
☐ Yes - please describe in the following space:

**3. Does your son/ daughter use any methods of contraception?**

☐ No
☐ Yes - please describe which method(s) and feel free to make any further comments:

**4. Please comment on any other issues.**

**Question 5 only needs to be filled out if your child is FEMALE.**
**If your child is male, please go to Section 7.**

**5. Does your daughter have any problem in managing her menstrual periods?**

☐ No
☐ Yes, please feel free to make any comments about variations in functioning, symptoms, any aspect of your daughter relating to her menstrual cycle and about how her periods are managed.

# SECTION 7: SCHOOLING & POST SCHOOL OPTIONS

**STILL ATTENDING SCHOOL** - please answer questions 1-3
**NO LONGER AT SCHOOL** - please go to question 4

**1. What type of school setting does your son or daughter attend?**

☐ Mainstream school (Government)

☐ Education Support Unit within a mainstream school (Government)

☐ Education Support School

☐ Home Schooling

☐ Mainstream school (Private)

☐ Education Support Unit within a mainstream school (Private)

☐ Education Support Centre

Other____________________________
(eg. School of the air)

**2. Approximately how long has your son/ daughter been attending their current school?**

☐ Less than 2 years

☐ 2-5 years

☐ More than 5 years

**3. Has your son/ daughter changed schools in the last two years?**

☐ Yes ☐ No

If Yes, please comment on the reason for the change:

____________________________________________________________

____________________________________________________________

**Please GO TO SECTION 8**
**if your son/ daughter is still attending school**

# NO LONGER AT SCHOOL

**4. How long since your son/daughter left school?**

☐ **< 1 year** ☐ **1-2 years** ☐ **3-5 years** ☐ **>5 years**

**5. Which statement best describes your son/ daughter's typical week day**
*(please tick **all applicable** and enter number of hours if also applicable)*

☐ Not working, but remaining home all day

☐ Taking part in activities funded through Post School Options (provides support for people who are unable to maintain full-time paid employment) eg leisure activities, volunteer work

☐ In a sheltered workshop/ business services environment for ____________ hours per week

☐ Attending post secondary school classes in a TAFE-like college environment_______ hours per week

☐ In an open work environment for ____________ hours per week

Other (please specify)_______________________________________________

**6. Ideally how would you like to see your son/ daughter spend their day?**
*(please tick **all applicable** and enter number of hours if also applicable)*

☐ Not working, but remaining home all day

☐ Taking part in activities funded through Post School Options

☐ In a sheltered workshop/ business services environment for ____________ hours per week

☐ Attending post secondary school classes in a TAFE-like college environment_______ hours per week

☐ In an open work environment for ____________ hours per week

Other (please specify)_______________________________________________

**6a. If the ideal does not match reality can you tell us why** ________________________________

____________________________________________________________________________________

____________________________________________________________________________________

**7. How many different day activity options did you have to choose from? (where day activity options provide support for people who are not in full time paid employment) eg. leisure activities, volunteer work** *(Please tick your response)*

☐ None (go to 7a) ☐ 1 (go to 7a) ☐ 2 – 5 (go to 7b) ☐ > 5 (go to 7b) ☐ Can't recall (go to 8)

**7a. If no day activity options or only one day activity option was available, please explain why below (e.g. small town no options, no transport available)**

____________________________________________________________________________________

____________________________________________________________________________________

**7b. If more than one day activity option was available, please explain what factor/s led you to choose the option/s you did for your son/daughter's day activities (e.g. more community orientated activity, one on one support etc.)**

____________________________________________________________________________________

____________________________________________________________________________________

**8. Do you feel that your son/daughter's needs are being met under the current day activity arrangements?**

☐ No - please describe what these needs are, and if possible how they could be met, in the space below

☐ Yes - please go to Question 9.

☐ Unsure - please comment:

**9. Is your son/daughter currently in paid employment, or have they been in paid employment within the last 12 months?**

☐ No - **please go to Question 10.**

☐ Yes - please give details in the table below of all the positions held by your son/daughter in the last 12 months, and complete questions 9a - 9d

| Job title | Number of hours per week | Period of employment | Gross annual income |
|---|---|---|---|
| | **Example answer** | | |
| Nursery attendant | 20 | Jan 2008 - present | $15, 000 |
| | **Your answer** | | |
| | | | |
| | | | |
| | | | |
| | | | |

**9a. How did your son/daughter secure his/her current job (or his/her most recent job if s/he is no longer employed)? *(Please tick all that apply)***

☐ Through work experience at school

☐ Through an employment agency (Name of agency________________________________)

☐ Through friends or family

☐ By independently applying for an advertised position

☐ Other:________________________________________________

**9b. Did your son/daughter undergo training for this job?**

☐ No - **please go to Question 9c.**

☐ Yes - please give details of what this training involved:

**9c. Does your son/daughter require ongoing support in this job?**

☐ No - **please go to Question 9d.**
☐ Yes - please give details of what this support involves and who provides it (eg. agency, family):

---

**9d. Please rate your son/daughter's level of satisfaction in this job (circle a number), then go to Question 12.**

| Not at all satisfied | | | | | | | Extremely satisfied |
|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

**10. Please indicate the main reason(s) why your son/daughter is not currently employed** ***(Tick all that apply):***

☐ Not ready for work
☐ Not willing to work
☐ Poor physical health
☐ Changes in funding
☐ Funding not available
☐ No appropriate job vacancies
☐ Has high support needs
☐ Has difficult/challenging behaviours
☐ Transport difficulties
☐ Insufficient services
☐ Inadequate services
☐ Problems at previous workplace - Please describe: ______________________

Other:______________________

**11. Has your son/daughter ever attempted to gain employment in the past?**

☐ No
☐ Yes - but s/he was unsuccessful in gaining employment
☐ Yes - s/he was successful in gaining employment but no longer works

**12. Do you feel that your son/daughter's employment needs are being met?**

☐ Yes - please comment on how your needs are being met:
☐ No - please comment:

**13. Please feel free to make any further comments about employment.**

# SECTION 8: ACCOMMODATION NEEDS

*This section asks where your child currently lives, any plans or expectations you may have to change the current situation in the future, and any issues arising for individuals living in out-of-family-home accommodation.*
*This information is important for informing and improving service needs.*

**1. Please indicate which of the following options best describes your son/daughter's usual place of residence.**

☐ Family home (ie., with parents) - **please go to Question 2.**
☐ Group home type accommodation - **please go to Question 4.**
☐ Hostel - **please go to Question 4.**
☐ Hospital or nursing home - **please go to Question 4.**
☐ Unit or house, living with other relatives and/or friends - **please go to Question 4.**
☐ Unit or house, living alone - **please go to Question 4.**
☐ Other: ________________________________ - **please go to Question 4.**

**2. What are your plans or expectations about your son/daughter moving into out-of-family-home accommodation in the future?** *(Please tick ONE option only)*

☐ Out-of-family-home accommodation will definitely not be wanted or needed for our child.
☐ We may consider out-of-family-home accommodation in the future, but only under extreme circumstances.
☐ We are undecided about out-of-family-home accommodation for our child.
☐ We may consider out-of-family-home accommodation for our child, but not for the next 20 years or so.
☐ We may consider out-of-family-home accommodation for our child in the next 10 years.
☐ We may consider out-of-family-home accommodation for our child in the next 5 years.
☐ We have been looking at accommodation options for our child - out of interest only at this stage.
☐ We have been looking at accommodation options for our child - seriously.
☐ We have applied for accommodation funding, and are awaiting the outcome.
☐ We applied for accommodation funding, but we were unsuccessful.
☐ We have received accommodation funding and are in the process of organising accommodation options for our child.

**2a. Please comment in the space below about why you will or will not consider out-of-family home accommodation for your son/daughter, and any concerns you may have about it. If you applied for funds but were unsuccessful, please also comment on the reasons given:**

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

**2b.** **If you plan or expect to consider out-of-family-home accommodation for your son/daughter in the future, what kind of support services do you think would help extend the period of time your child could stay in the family home?**

________________________________________________

________________________________________________

________________________________________________

________________________________________________

**3.** **Does your son/daughter spend time overnight in a place other than the family home on a regular basis?**

☐ No - **please go to Question 6.**

☐ Yes - please indicate where s/he stays and how often in the table below:

| **Place of accommodation** | **How often does s/he stay there?** |
|---|---|
| **Example answers** | |
| Aunt's house | 1 night per week |
| **Your answer** | |
| | |
| | |
| | |
| | |

**Questions 4 - 5 are to be filled out only if your child does NOT live in the family home. If your child lives in the family home, please go to Question 6.**

**4.** **Please indicate which of the following options best describe(s) the reasons why you sought out-of-family-home accommodation for your son/daughter.**
***(Please tick all applicable options)***

☐ Change of personal circumstances (e.g., death in family, illness)
☐ Change in service provision (e.g., left school, change in respite services or day activities)
☐ Your child's challenging behaviours were difficult to manage at home
☐ Your child's high support needs were difficult to manage at home
☐ Your child wanted to live more independently
☐ Your child moved to be closer to his/her work
☐ Caring for your child at home was causing high levels of stress/exhaustion in your family unit
☐ Caring for your child at home was causing financial difficulties
☐ Family/marital problems
☐ Other:________________________________

**4a. Do you think your son/daughter would have stayed longer in the family home if you had access to more support services in the home?**

☐ No

☐ Yes - please indicate what kind of services may have extended the period of time that your son/daughter stayed at home:

**5. Does your son/daughter receive residential care or support (eg., from support person, other than family/ unpaid carer) who visit his/her home regularly)?**

☐ No - **please go to Question 6.**

☐ Yes - please describe who provides the care and how often

**6. Do you feel that your son/daughter's accommodation needs are being met?**

☐ Yes

☐ No - please comment on what his/her needs are and if possible, how they could be met in the space below:

**7. Please feel free to make any further comments about accommodation.**

# SECTION 9: EVERYDAY FUNCTIONING

**Please tick the box that best describes YOUR SON/ DAUGHTER's <u>BEST</u> level of functioning**

**ADDITIONAL CONDITIONS**

**1. Vision (Tick *ONE* only)**

- a. Normal vision (include glasses)...................................................... ☐
- b. Partial sight - problems in mobility.................................................. ☐
- c. Blind for all practical purposes...................................................... ☐

**2. Hearing (Tick *ONE* only)**

- a. Normal hearing (including deafness in one ear).................................. ☐
- b. Partial hearing; hearing aid prescribed........................................... ☐
- c. Profoundly deaf - only residual hearing........................................... ☐

**3. Epilepsy (Tick *ONE* only)**

- a. No fits - no medication................................................................ ☐
- b. Has or had fits; taking medication to control fits, not real problem at present........................................................................ ☐
- c. Has or had fits; taking medication to control fits, recurring problem at present........................................................................ ☐

**COMMUNICATION SKILLS**

**4. Instructions (Tick *ONE* only)**

- a. Can remember to carry out a sequence of instructions e.g. a shopping list or directions to a place........................................ ☐
- b. Can remember instructions and carry out later, e.g. a message from work.......................................................... ☐
- c. Follows a simple instruction that can be carried out there and then e.g. "switch on the light"................................................... ☐
- d. No response when talked to, except to own name................................ ☐

**5. Communication - Speech (Tick *ONE* only)**

- a. Speaks well - intelligible to all; uses appropriate language; able to give accurate information.............................................................................. ☐
- b. Some difficulty in speaking - lack of clarity or fluency (e.g may tend to stammer), but language appropriate...................................... ☐

**Please go to Question 7 if answering a or b**

- c. Difficulty in speech – only intelligible to those who know him/her well............. ☐
- d. Does not use speech to communicate................................................ ☐

**Please go to Question 6 if answering c or d**

**6. Nonverbal Communication - e.g gestures, signs, Compic, assisted communication devices (Tick *ONE* only)**

a. Communicates well nonverbally........................................................ ☐

b. Some difficulty in nonverbal communication........................................... ☐

c. Unable to communicate nonverbally................................................... ☐

Please describe method/s of communication used____________________________________

**SELF-CARE SKILLS**

**7. Eating (Tick *ONE* only)**

a. Feeds self and can manage all activities at table with no problem.............. ☐

b. Feeds self and can manage most activities (e.g. cutting meat) but needs some guidance/ help........................................................... ☐

c. Feeds self completely but needs help in seasoning foods, cutting meat etc.......................................................................... ☐

d. Needs to be fed or if alone is a messy feeder..................................... ☐

**8 . Personal Needs (Tick *ONE* only)**

a. Can look after his/her personal needs *completely independently* - cleanliness, toilet, dressing and chooses appropriate clothes.................. ☐

b. Generally looks after personal needs but requires checking and reminding......................................................................... ☐

c. Has to be helped to wash, dress etc................................................ ☐

d. Dependent on other persons for all personal needs.............................. ☐

**9 . Mobility (Tick *ONE* only)**

a. Able to walk, run and climb stairs with no difficulty................................ ☐

b. Able to walk fair distances (around one kilometre) but finds running and climbing stairs difficult................................................ ☐

c. Can walk only short distances; tires easily.......................................... ☐

d. Unable to walk alone................................................................ ☐

**10 . Use of Hands (Tick *ONE* only)**

a. Fully competent use of hands and fingers - can hit a nail with a hammer, thread needle, use tin opener........................................... ☐

b. Manages most day-to-day activities involving hands, doing up buttons, using knife and fork, ties shoelaces...................................... ☐

c. Slow and rather clumsy in using hands but manages some day-to-day activities....................................................................... ☐

d. Only capable of very basic hand skills or not at all................................ ☐

### 11 . Around the House (Tick *ONE* only)

a. Capable of doing most jobs around the house without supervision - makes bed, washes and dries dishes, cleans the floor etc...................... ☐

b. Attempts most jobs but needs supervision and help to complete the job properly......................................................................... ☐

c. Able to do simple repetitive jobs - setting the table, dries dishes................ ☐

d. Attempts these simple jobs but cannot do them properly.......................... ☐

e. Unable to do any household jobs................................................... ☐

### 12 . Preparing Food (Tick *ONE* only)

a. Can prepare an adequate variety of meals without supervision................. ☐

b. Prepares simple hot food without supervision - makes eggs, warms soup....... ☐

c. Makes up food which does not require cooking or with which he/she is familiar - cereals and sandwiches.................................................. ☐

d. With supervision, can prepare simple foods......................................... ☐

e. Needs all food prepared for him/her................................................. ☐

## COMMUNITY SKILLS

### 13 . Reading (Tick *ONE* only)

a. Can read and follow a series of written instructions, e.g. directions on a packet of food, recipes........................................................... ☐

b. Can read and act appropriately to signs giving directions in shops or in the streets.................................................................................. ☐

c. Recognise own name written down................................................... ☐

d. Recognise and pick out around six different labels on tins and boxes of foods, e.g.cereals, washing powders.............................................. ☐

### 14 . Writing (Tick *ONE* only)

a1. Has good writing skills eg writes stories, letters .................................. ☐

a Can write short notes, e.g. shopping lists.......................................... ☐

b. Can write own name and address without help.................................... ☐

c. Writes full name without help......................................................... ☐

d. Writes name and address from copy................................................. ☐

e. Unable to write........................................................................... ☐

## 15 . Time (Tick *ONE* only)

a. Regularly uses watch or clock to check timing of activities e.g. when a friend might call........................................................ ☐

b. Tells time in hours and minutes, with clock or watch.............................. ☐

c. Knows what hour it is by the clock.................................................. ☐

d. Shows by behaviour that he/she can anticipate some events of the day e.g. start of a television programme................................................ ☐

## 16 . Money (Tick *ONE* only)

a. Able to use money responsibly - no difficulty in coping with everyday money transactions; giving right amount and checking change.................. ☐

b. Can select the amount of money appropriate to stated price of article......... ☐

c. Estimates roughly what different amounts might buy, e.g. if given 50 cents has some idea of what he/she could get for that.......................... ☐

d. Picks out coins by name, e.g. 50 cents, 10 cents................................ ☐

e. No understanding of money......................................................... ☐

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## 17 . Telephone (Tick *ONE* only)

a. Your son/daughter successfully answers and makes phone calls to/from both familiar and unfamiliar people almost all of the time........................... ☐

b. Your son/ daughter answers phone calls successfully almost all of the time, and can make phone calls to both familiar and unfamiliar people if s/he prepares what s/he is going to say first (eg. by writing it down)................. ☐

c. Your son/daughter successfully answers and makes phone calls most of the time, but sometimes requires prompting or assistance particularly to/from unfamiliar people OR successfully answers and makes phone calls to relatives and friends without supervision but will not make calls to unfamiliar people................... ☐

d. Your son/daughter successfully answers and makes phone calls to relatives and/or friends about 25-90%............................................... ☐

e. Your son/daughter successfully answers and makes phone calls to relatives and/or friends less than 25% of the time............................................ ☐

f. Your son/daughter will not use the phone at all...................................... ☐

**18 . Social Events (Tick *ONE* only)**

- a. Your son/daughter deals with a range of social events independently ☐
- b. Your son/daughter deals with a range of social events independently, but you are concerned for his/her safety ☐
- c. Your son/daughter deals with a range of social events independently, but s/he requires supervision on some occasions, particularly when attending an unfamiliar event or planning an event ☐
- d. Your son/daughter deals with about 50-90% of his/her social events; for the remainder s/he requires help or supervision ☐
- e. Your son/daughter deals with less than 25% of his/her social events; for the remainder s/he requires help or supervision ☐

**19 . New Skills (Tick *ONE* only)**

- a. Your son/daughter is able to learn a new skill or routine very quickly without extra help ☐
- b. Your son/daughter is able to learn a new skill or routine without extra help, but may take longer than others ☐
- c. Your son/daughter is able to learn a new skill or routine most of the time, but needs extra help or supervision if the task is fairly difficult ☐
- d. Your son/daughter can learn a new skill or routine about 25-90% of the time; the rest of time s/he needs extra help or supervision or cannot learn it at all ☐
- e. Your son/daughter can learn a new skill or routine less than 25% of the time; the rest of time s/he needs extra help or supervision or cannot learn it at all ☐

**20 . Public Transport (Tick *ONE* only)**

- a. Your son/daughter is able to use public transport independently on both familiar and unfamiliar routes ☐
- b. Your son/daughter is able to use public transport independently on both familiar and unfamiliar routes but you are concerned for his/her safety ☐
- c. Your son/daughter is able to use public transport independently on familiar route(s), but requires supervision on unfamiliar routes ☐
- d. Your son/daughter is able to use public transport on familiar routes about 25-90% of the time; the rest of time s/he needs supervision ☐
- e. Your son/daughter is able to use public transport on familiar routes less than 25% of the time ☐
- f. Your son/daughter always requires supervision when using public transport OR your son/daughter refuses to use public transport OR you do not allow your son/daughter to use public transport ☐

# SECTION 10: SOCIAL RELATIONSHIPS & ACTIVITIES

*Friendships and participation in social / leisure activities are important for young people and may change after their transition from school.*

**1. In which social/ recreational activities outside of the home is your son/ daughter involved?** *(please tick all applicable)*

☐ Clubs

☐ Formal sporting activities or teams

☐ Youth group activities organised by church or advocacy groups

☐ Volunteer activities

☐ Particular activities for individuals with special needs

☐ Other________________________________________

☐ None

**2. What makes it easy for your son/ daughter to participate in social recreation activities? (eg. inclusive sporting club, easy accessible transport, small town where all know each other)**

____________________________________________________

____________________________________________________

____________________________________________________

**3. What makes it hard for your son/ daughter to participate in social recreation activities? (eg. transport, safety risks)**

____________________________________________________

____________________________________________________

____________________________________________________

**4. Please list how often your son/ daughter takes part in activities outside the home. If s/he does not participate in any sports or activities, leave the table blank.**

| **Type of activity** | **Never** | **Once / twice per year** | **Every few months** | **Once / twice a month** | **Once a week** |
|---|---|---|---|---|---|
|  | ☐ | ☐ | ☐ | ☐ | ☐ |
|  | ☐ | ☐ | ☐ | ☐ | ☐ |
|  | ☐ | ☐ | ☐ | ☐ | ☐ |
|  | ☐ | ☐ | ☐ | ☐ | ☐ |
|  | ☐ | ☐ | ☐ | ☐ | ☐ |

**5 With whom does your son/ daughter participate in these activities?**
*(please tick all applicable)*

☐ Similar aged peers without disabilities

☐ Peers with disabilities

☐ Friend of the family /neighbour/ church member

☐ Paid employee (support person, recreational aide)

☐ Sibling with/ without sibling's friends

☐ Other relatives

☐ Parents

☐ Other

**6. Does your son/ daughter's social network contain**

☐ No friends ☐ 1 or 2 close friends ☐ Between 3 and 6 close friends ☐ More than 6 close friends

**7. Does your son/ daughter's social network contain more friends with or without disabilities?**

☐ Without disabilities ☐ With disabilities ☐ Not applicable

**8. How frequently does your son/ daughter have the opportunity to interact in social activities with peers without disabilities?**

☐ Never ☐ Rarely ☐ Sometimes ☐ Frequently ☐ Almost always

**9. How frequently does your son/ daughter have the opportunity to interact in social activities with peers with disabilities?**

☐ Never ☐ Rarely ☐ Sometimes ☐ Frequently ☐ Almost always

**10. How frequently does your son/ daughter have the opportunity to interact in social activities with family members and relatives?**

☐ Never ☐ Rarely ☐ Sometimes ☐ Frequently ☐ Almost always

**Questions 11 -13 should be filled out only if your son/ daughter is NO LONGER AT SCHOOL.**
**If your son/ daughter is still at school please go to Section 11.**

**11. Did leaving school affect the number of friends your son/ daughter has?**

☐ No, same number of friends
☐ Yes, has fewer friends than s/he had at school
☐ Yes, has more friends than s/he had at school

**12. Did leaving school affect the quality of the friendships your son/ daughter has?**

☐ No
☐ Yes - please comment on how the friendships have been affected in the space below:

**13. Please feel free to make any further comments on the impact of leaving school on your son/ daughter's social circle.**

# SECTION 11: PERSONALITY & BEHAVIOUR

*Your son/daughter's strengths as well as any problems s/he may have with his/her emotions and behaviour are very important in relation to outcomes. We use a well documented measure of behaviour which allows for comparison with other young people.*

**a. Please list your son/daughter's strengths.**

______________________________________________

______________________________________________

______________________________________________

______________________________________________

**b. What do other people like about him/her?**

______________________________________________

______________________________________________

______________________________________________

______________________________________________

Many of the following behaviours may not apply to your son/daughter. For each item that does describe your son/daughter, now or within the PAST SIX MONTHS, please circle the **2** if the item is **very true** or **often true.** Circle **1** if the item is **somewhat or sometimes true** of your son/daughter. If the item is **not true** of your child circle the **0.**

**0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true**

If your son/daughter is unable to perform an item, circle the **0.** For example, if your child has no speech, then for the item "Talks too much or too fast" circle the **0.**

| | **Please circle** | | | |
|---|---|---|---|---|
| **1.** | **0** | **1** | **2** | Appears depressed, downcast or unhappy. |
| **2.** | **0** | **1** | **2** | Avoids eye contact. Won't look you straight in the eye. |
| **3.** | **0** | **1** | **2** | Aloof, in his/her own world. |
| **4.** | **0** | **1** | **2** | Abusive. Swears at others. |
| **5.** | **0** | **1** | **2** | Arranges objects or routine in a strict order.<br>Please describe:______________________________ |
| **6.** | **0** | **1** | **2** | Bangs head. |
| **7.** | **0** | **1** | **2** | Becomes over-excited. |
| **8.** | **0** | **1** | **2** | Bites others. |
| **9.** | **0** | **1** | **2** | Bizarre speech. Please describe:______________________________<br>______________________________________________ |
| **10.** | **0** | **1** | **2** | Cannot attend to one activity for any length of time, poor attention span. |

**0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true**

**11.** **0** **1** **2** Chews or mouths objects, or body parts.

**12.** **0** **1** **2** Cries easily for no reason, or over small upsets.

**13.** **0** **1** **2** Covers ears or is distressed when hears particular sounds.
Please describe:______________________________________

**14.** **0** **1** **2** Confuses the use of pronouns, eg. uses "you" instead of "I".

**15.** **0** **1** **2** Deliberately runs away.

**16.** **0** **1** **2** Delusions: has a firmly held belief or idea that can't possibly be true.
Please describe:______________________________________

**17.** **0** **1** **2** Distressed about being alone.

**18.** **0** **1** **2** Doesn't show affection.

**19.** **0** **1** **2** Doesn't respond to others' feelings, eg. shows no response if a family member is crying.

**20.** **0** **1** **2** Easily distracted from his/her task, eg. by noises.

**21.** **0** **1** **2** Easily led into trouble by others.

**22.** **0** **1** **2** Eats non-food items, eg. dirt, grass, soap.

**23.** **0** **1** **2** Excessively distressed if separated from familiar person.

**24.** **0** **1** **2** Fears particular things or situations, eg. the dark or insects.
Please describe:______________________________________

**25.** **0** **1** **2** Facial twitches or grimaces.

**26.** **0** **1** **2** Flicks, taps, twirls objects repeatedly.

**27.** **0** **1** **2** Fussy eater or has food fads.

**28.** **0** **1** **2** Gorges food. Will do anything to get food, eg. takes food out of bins or steals food.

**29.** **0** **1** **2** Gets obsessed with an idea or activity.
Please describe:______________________________________

**30.** **0** **1** **2** Grinds teeth.

**31.** **0** **1** **2** Has become confused or forgetful

**32.** **0** **1** **2** Has become more withdrawn

**33.** **0** **1** **2** Has nightmares, night terrors or walks in sleep.

**34.** **0** **1** **2** Has temper tantrums, eg. stamps feet, slams doors.

**35.** **0** **1** **2** Hides things.

**36.** **0** **1** **2** Hits self or bites self.

**37.** **0** **1** **2** Hums, whines, grunts, squeals, or makes other non-speech noises.

**0 = not true as far as you know   1 = somewhat or sometimes true   2 = very true or often true**

| | | | | |
|---|---|---|---|---|
| **38.** | **0** | **1** | **2** | Impatient. |
| **39.** | **0** | **1** | **2** | Inappropriate sexual activity with another. |
| **40.** | **0** | **1** | **2** | Increase in appetite |
| **41.** | **0** | **1** | **2** | Impulsive, acts before thinking. |
| **42.** | **0** | **1** | **2** | Irritable. |
| **43.** | **0** | **1** | **2** | Jealous. |
| **44.** | **0** | **1** | **2** | Kicks, hits or injures others. |
| **45.** | **0** | **1** | **2** | Lacks self-confidence, poor self-esteem. |
| **46.** | **0** | **1** | **2** | Laughs or giggles for no obvious reason. |
| **47.** | **0** | **1** | **2** | Lights fires. |
| **48.** | **0** | **1** | **2** | Likes to hold or play with an unusual object, eg. string, twigs; overly fascinated with something, eg. water.<br>Please describe:________________________________________ |
| **49.** | **0** | **1** | **2** | Loss of appetite. |
| **50.** | **0** | **1** | **2** | Loss of enjoyment or interest in usual activities |
| **51.** | **0** | **1** | **2** | Loss of self-care skills |
| **52.** | **0** | **1** | **2** | Makes gloomy statements. |
| **53.** | **0** | **1** | **2** | Masturbates or exposes self in public. |
| **54.** | **0** | **1** | **2** | Mood changes rapidly for no apparent reason. |
| **55.** | **0** | **1** | **2** | Moves slowly, underactive, does little, eg. only sits and watches others. |
| **56.** | **0** | **1** | **2** | Noisy or boisterous. |
| **57.** | **0** | **1** | **2** | Not communicating as much as usual |
| **58.** | **0** | **1** | **2** | Overactive, restless, unable to sit still. |
| **59.** | **0** | **1** | **2** | Overaffectionate. |
| **60.** | **0** | **1** | **2** | Overbreathes, vomits, has headaches or complains of being sick for no physical reason. |
| **61.** | **0** | **1** | **2** | Overly attention-seeking. |
| **62.** | **0** | **1** | **2** | Overly interested in looking at, listening to or dismantling mechanical things, eg. lawnmower, vacuum cleaner. |
| **63.** | **0** | **1** | **2** | Panics. Sweats, flushes, trembles. |
| **64.** | **0** | **1** | **2** | Poor sense of danger. |

**0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true**

| | | | | |
|---|---|---|---|---|
| **65.** | **0** | **1** | **2** | Prefers to do things on his/her own. Tends to be a loner. |
| **66.** | **0** | **1** | **2** | Preoccupied with only one or two particular interests.<br>Please describe:______________________________ |
| **67.** | **0** | **1** | **2** | Problems with cigarettes, alcohol or caffeine. |
| **68.** | **0** | **1** | **2** | Problems with the illegal use of drugs |
| **69.** | **0** | **1** | **2** | Refuses to go to college, activity centre or workplace. |
| **70.** | **0** | **1** | **2** | Repeated movements of hands, body, head or feet, eg. handflapping or rocking. |
| **71.** | **0** | **1** | **2** | Resists being cuddled, touched or held. |
| **72.** | **0** | **1** | **2** | Repeats back what others say like an echo. |
| **73.** | **0** | **1** | **2** | Repeats the same word or phrase over and over. |
| **74.** | **0** | **1** | **2** | Smells, tastes, or licks objects. |
| **75.** | **0** | **1** | **2** | Scratches or picks his/her skin. |
| **76.** | **0** | **1** | **2** | Screams a lot. |
| **77.** | **0** | **1** | **2** | Sleeps too little. Disrupted sleep. |
| **78.** | **0** | **1** | **2** | Stares at lights or spinning objects. |
| **79.** | **0** | **1** | **2** | Sleeps too much or overly drowsy. |
| **80.** | **0** | **1** | **2** | Soils outside toilet though toilet trained. Smears or plays with faeces. |
| **81.** | **0** | **1** | **2** | Speaks in whispers, high pitched voice, or other unusual tone or rhythm. |
| **82.** | **0** | **1** | **2** | Spits. |
| **83.** | **0** | **1** | **2** | Switches lights on and off, pours water over and over; or similar repetitive activity.<br>Please describe:______________________________ |
| **84.** | **0** | **1** | **2** | Steals |
| **85.** | **0** | **1** | **2** | Stubborn, disobedient or uncooperative. |
| **86.** | **0** | **1** | **2** | Shy. |
| **87.** | **0** | **1** | **2** | Strips off clothes or throws away clothes. |
| **88.** | **0** | **1** | **2** | Says he/she can do things that he/she is not capable of. |
| **89.** | **0** | **1** | **2** | Stands too close to others. |
| **90.** | **0** | **1** | **2** | Sees, hears, something which isn't there. Hallucinations.<br>Please describe:______________________________ |

**0 = not true as far as you know    1 = somewhat or sometimes true    2 = very true or often true**

| | | | | |
|---|---|---|---|---|
| **91.** | **0** | **1** | **2** | Talks about or attempts suicide. |
| **92.** | **0** | **1** | **2** | Talks too much or too fast. |
| **93.** | **0** | **1** | **2** | Talks to self or imaginary people or objects. |
| **94.** | **0** | **1** | **2** | Tells lies. |
| **95.** | **0** | **1** | **2** | Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow. |
| **96.** | **0** | **1** | **2** | Tense, anxious, worried. |
| **97.** | **0** | **1** | **2** | Throws or breaks objects. |
| **98.** | **0** | **1** | **2** | Tries to manipulate or provoke others. |
| **99.** | **0** | **1** | **2** | Under-reacts to pain. |
| **100.** | **0** | **1** | **2** | Unrealistically happy or elated. |
| **101.** | **0** | **1** | **2** | Unusual body movements, posture, or way of walking.<br>Please describe:_______________________________________ |
| **102.** | **0** | **1** | **2** | Upset and distressed over small changes in routine or environment.<br>Please describe:_______________________________________ |
| **103.** | **0** | **1** | **2** | Urinates outside toilet, although toilet trained. |
| **104.** | **0** | **1** | **2** | Very bossy. |
| **105.** | **0** | **1** | **2** | Wanders aimlessly. |
| **106.** | **0** | **1** | **2** | Whines and complains a lot. |
| **107.** | **0** | **1** | **2** | Overall, do you feel that your child has problems with feelings or behaviour, in addition to problems with development? If not, please circle the **0**. If so, but they're minor, please circle the **1**. If they're major problems, please circle the **2**. |

Please write in any problems he/she has that were not listed above:

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

**Please feel free to make any further comments** ______________________________

_______________________________________________________________

*Acknowledgement: Einfeld & Tonge, 1993.*

# SECTION 12A: TRANSITION TO ADULTHOOD

***Please only answer this section if your child is <u>still at school</u>***
***If your child has left school please GO TO Section 12B***

**1. Have you had any meetings or discussions between your family and teachers to discuss your son/daughter's transition from school (eg. Individual Transition Plan, Individual Education Plan)?** *(Please tick your response)*

☐ Yes, within the last 6 months ☐ Yes, within the last year

☐ Yes, within the last 2 years ☐ No, there has not been one yet

☐ Other (please specify)________________________________________

____________________________________________________________

**2. What type of activities is your son/ daughter's school program incorporating into their school day/life to facilitate transition.** (*Please tick all applicable)*

☐ Specific careers classes
☐ Work experience in a community setting
☐ Work experience on the school site (eg. work in garden, library)
☐ Specific courses related to developing vocational skills development (eg.work skills, horticulture)
☐ Specific Vocation Education Training (VET) courses eg. Certificate I
☐ Specific courses at TAFE
☐ Daily living skills instruction (eg. cooking, cleaning, shopping)
☐ Social skills instruction (eg. how to talk to customers, meet friends)
☐ Community based learning (eg. using public transport)
☐ Other (please specify)________________________________________

____________________________________________________________

**3. Are you aware of any adult services in the community to assist your son/daughter once he/she leaves school?**

☐ **Yes** ☐ **No**

**Specifically, do you have knowledge of the following services which may be available to your son/ daughter after they leave school** (*Please tick all applicable);*

**and how did you find out this information**

| Services | Teachers | DSC (eg LAC) | Other service provider | Parent support group | Own research | Other eg parents/ friends |
|---|---|---|---|---|---|---|
| ☐ Accommodation/ community living options | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Paid Work in open employment | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Work in Business Services (previously sheltered workshops) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Volunteer work | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Day Activity Programs (eg. Alternatives to Employment) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Recreation/ Leisure Activities | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Support Groups for son/daughter | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Advocacy Agencies (eg. People with Disabilities) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Parent support organisations (eg DSWA) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Health and Medical Services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Therapy Services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Post School Options Funding | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Continuing Education Opportunities (eg TAFE) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

If 'Other', please specify: ____________________________________________

**4. Which of the following would be helpful as you plan for your son/ daughter's transition from high school?** (*Please tick all applicable*)

☐ More information about your son/ daughter's school transition program
☐ More information about your son/ daughter's skill level
☐ More information about accommodation / community living options
☐ More information about work in open employment ☐ Business Services ☐ Volunteer Work
☐ More information about financial assistance eg. employment / day options
☐ Information about how to build and maintain informal community-based support
☐ Consistency in service representation (eg dealing with one person)
☐ Family support group (eg DSWA) ☐ More information about TAFE education
☐ Increased emotional support and encouragement from your extended family
☐ I do not think I need any help

Other____________________________

**5. What kind of involvement do you have as your son/ daughter transitions from high school?**

(a) **Phone/ written or face to face contact with teacher**

☐ Once a week ☐ Once a month

☐ Once every 12 months ☐ As required

(b) **How involved are *you* in decision making during transition planning**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

(c) **How involved is your *son/ daughter* in decision making during transition planning**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

Comments________________________________________________________

(d) **How involved are *you* in finding potential job placements for your son/ daughter**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely ☐ Not applicable

(e) **How involved is your *son/ daughter* in finding potential job placements**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely ☐ Not applicable

Comments________________________________________________________

(f) **How involved are *you* in finding potential accommodation/ community living options for your son/ daughter**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely ☐ Not applicable

(g) **How involved is your *son/ daughter* in finding potential accommodation /community living options**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely ☐ Not applicable

Comments________________________________________________________

**6a. Would *you* like to be more involved in** *(please tick all applicable)*

☐ Transition planning ☐ Finding job placements

☐ Finding potential accommodation/community living options

**6b. Would you like *your son/ daughter* to be more involved in** *(please tick all applicable)*

☐ Transition planning ☐ Finding job placements

☐ Finding potential accommodation/community living options

Comments________________________________________________________

**7. Two years after your son/ daughter leaves school, how would you like to see them spend their day?**

*(please tick all applicable and state number of hours if also applicable)*

☐ Not working, but remaining home all day

☐ In a day program

☐ In a sheltered workshop/ business services environment for ____________ hours per week

☐ Attending post secondary school classes in a TAFE-like college environment

☐ In an open work environment for _______________ per week

Other (please specify)____________________________________________

**8. Do you anticipate these expectations will be met?** *(please tick your response)*

☐ Yes ☐ No ☐ Don't know

Please comment on why______________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

**9. How much do you think/worry about the following issues for your son/ daughter as they make the transition from high school** *(Please tick one response for each question)*

| | | | | | |
|---|---|---|---|---|---|
| Transition issues in general | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Work/ Day activities | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Living arrangements | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Access to social activities and friends | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Future care/living arrangements for your son /daughter | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Other_____________________ | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |

Comments__________________________________________________________________________

________________________________________________________________________________

**10. How much have your worries and concerns regarding transition issues affected your own daily life and well- being?**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

Can you please comment on ***how you*** are affected________________________________________

____________________________________________________________________________

**11. How much have your worries and concerns regarding transition issues affected daily life and well- being of the family in general ?**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

Can you please comment on ***how your family*** is affected__________________________________

____________________________________________________________________________

**12. Can you reflect on how you feel about your son/ daughter moving out of the school system? Perhaps moving out into the community, getting a job, and so forth.**

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

Reference: Kraemer, B. R., & Blacher, J. (2001).

**13. In thinking about your son/ daughter please indicate , *as best you can*, how much you feel <u>HE /SHE</u> is satisfied or dissatisfied with the following,**

1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4= satisfied and 5 = very satisfied

| | Very dissatisfied | | | | Very satisfied |
|---|---|---|---|---|---|
| (a) to what extent his/her health needs are catered for? | 1 | 2 | 3 | 4 | 5 |
| (b) His/ her relationship with family members | 1 | 2 | 3 | 4 | 5 |
| (c) His/her relationships with other people outside the family | 1 | 2 | 3 | 4 | 5 |
| (d) With his/ her daytime activities | 1 | 2 | 3 | 4 | 5 |
| (e) How safe he/ she feels | 1 | 2 | 3 | 4 | 5 |
| (f) His/ her feeling part of the community | 1 | 2 | 3 | 4 | 5 |
| (g) His/ her life as a whole | 1 | 2 | 3 | 4 | 5 |

Acknowledgement- Adaption of
Personal Wellbeing Index –Intellectual Disability 3rd Edition. Robert A. Cummins, Anna L.D. Lau 2005

**Please GO TO PART 2**

# SECTION 12B: TRANSITION TO ADULTHOOD

***Please only answer this section if your child has left school***

**1. What type of school setting did your son or daughter attend during the last five years of their school life?**

☐ Mainstream school (Government)

☐ Mainstream school (Private)

☐ Education Support Unit within a mainstream school (Government)

☐ Education Support Unit within a mainstream school (Private)

☐ Education Support School

☐ Education Support Centre

☐ Home Schooling

Other____________________________
(eg. School of the air)

**2. Do you recall if you had regular meetings or discussions between your family and teachers to discuss your son/daughter's transition from school life? (e.g. an Individual Education Plan)**

☐ Yes, within the last 6 months of school life

☐ Can't remember, too long ago

☐ Yes, within the last year of school life

☐ No, there was not one

☐ Yes, within the last 2 years

**2a. If you did have meetings, did you find them effective?** Yes ☐ No ☐

Comments____________________________________________________________

__________________________________________________________

**3. During the last two years of schooling, what type of activities did your son/ daughter's school program incorporate into their school day/life to facilitate transition.**
(*Please tick all applicable*)

☐ Specific careers classes

☐ Work experience in a community setting

☐ Work experience on the school site (eg. work in garden, library)

☐ Specific courses related to developing vocational skills development (eg.work skills, horticulture)

☐ Specific Vocation Education Training (VET) courses eg. Certificate I

☐ Specific courses at TAFE

☐ Daily living skills instruction (eg. cooking, cleaning, shopping)

☐ Social skills instruction (eg. how to talk to customers, meet friends)

☐ Community based learning (eg. using public transport)

☐ Other (please specify)______________________________________________

**4. While your son/ daughter was at school, were you aware of any adult services in the community to assist your son/daughter once he/she left school?**

☐ **Yes** ☐ **No**

**Specifically, did you have knowledge of the following services which may have been available to your son/ daughter after they left school** (*Please tick all applicable*)

**and how did you find out this information**

| Services | Teachers | DSC (eg LAC) | Other service provider | Parent support group | Own research | Other eg parents/ friends |
|---|---|---|---|---|---|---|
| ☐ Accommodation/ community living options | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Paid Work in open employment | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Work in Business Services (previously sheltered workshops) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Volunteer work | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Day Activity Programs (eg. Alternatives to Employment) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Recreation/ Leisure Activities | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Support Groups for son/daughter | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Advocacy Agencies (eg. People with Disabilities) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Parent support organisations (eg DSWA) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Health and Medical Services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Therapy Services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Post School Options Funding | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☐ Continuing Education Opportunities (eg TAFE) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Other, please specify____________________________________________

**5. Which of the following would have been helpful as you planned for your son/ daughter's transition from school?** *(Please tick all applicable)*

☐ More information about your son/ daughter's school transition program

☐ More information about your son/ daughter's skill level

☐ More information about accommodation / community living options

☐ More information about work in open employment ☐ Business Services ☐ Volunteer Work

☐ More information about financial assistance eg. employment / day options

☐ Information about how to build and maintain informal community-based support

☐ Consistency in service representation (eg dealing with one person)

☐ Family support group (eg DSWA) ☐ More information about TAFE education

☐ Increased emotional support and encouragement from your extended family

☐ I do not think I needed any help

Other________________________________________

**6a. Were there any other factors that assisted you when you were planning for your son/ daughter's transition from high school? (e.g. a particularly helpful person informing you about the options available for your son/ daughter such as a social worker or teacher)**

Comment____________________________________________________________

____________________________________________________________________

____________________________________________________________________

**6b. Were there any other factors that hindered you when you were planning for your son/ daughter's transition from high school? (e.g. no consistency in staff so you were repeating your needs to various people?)**

Comment____________________________________________________________

____________________________________________________________________

____________________________________________________________________

**7. What kind of involvement did you have as your son/ daughter transitioned from school?**

(a) **Phone/ written or face to face contact with teacher**

☐ Once a week ☐ Once a month ☐ Can't recall

☐ Once every 12 months ☐ As required

(b) **How involved were *you* in decision making during transition planning**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

(c) **How involved was your *son/ daughter* in decision making during transition planning**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

Comments____________________________________________________

(d) **How involved were *you* in finding potential job placements for your son/ daughter**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

☐ Not applicable

(e) **How involved was your *son/ daughter* in finding potential job placements**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

☐ Not applicable

Comments____________________________________________________

(f) **How involved were *you* in finding potential accommodation/ community living options for your son/ daughter**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

☐ Not applicable

(g) **How involved was your *son/ daughter* in finding potential accommodation /community living options**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

☐ Not applicable

Comments____________________________________________________

(h) **Would *you* like to have been more involved in** *(please tick all applicable)*

☐ Transition planning ☐ Finding job placements

☐ Finding potential accommodation/community living options

(i) **Would you like *your son/ daughter* to have been more involved in** *(please tick all applicable)*

☐ Transition planning ☐ Finding job placements

☐ Finding potential accommodation/community living options

Comments____________________________________________________

**8. Was there a plan for what your your son/ daughter would be doing once he/she left school ?**

☐ Yes ☐ No, ***go to question 10*** ☐ Can't recall, ***go to question 10***

**9. If yes,**

**when was the plan in place (How many months prior to exiting school?)**

☐ 0-3 months ☐ 3-6 months ☐ 6-12 months ☐ >1 year ☐ Can't recall

**who was involved in the plan***(eg therapist, teacher)*______________________________

☐ Can't recall ______________________________

**what was included in the plan** ______________________________

☐ Can't recall ______________________________

**were you satisfied with the plan** ☐ Yes ☐ No

Comment______________________________________________________

**10. Was there a lapse between exiting the school system and entering vocational, day placement or activity programs?**

☐ Yes ☐ No ☐ Can't recall

**11. If there was a lapse, how long was it?**

☐ 0-3 months ☐ 3-6 months ☐ 6-12 months ☐ >1 year

**12. How much did you think/worry about the following issues for your son/ daughter as they made the transition from high school** *(Please tick one response for each question)*

| | | | | | |
|---|---|---|---|---|---|
| Transition issues in general | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Work/ Day activities | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Living arrangements | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Access to social activities and friends | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Future care/living arrangements for your son /daughter | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |
| Other____________________ | ☐ Never | ☐ Rarely | ☐ Sometimes | ☐ Frequently | ☐ Very often |

Comments______________________________________________________

______________________________________________________

**13. How much have your worries and concerns regarding transition issues affected your own daily life and well- being?**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

Can you please comment on **how you** are/ were affected____________________________________

______________________________________________________________________

**14. How much have your worries and concerns regarding transition issues affected daily life and well- being of the family in general ?**

☐ Not at all ☐ A little ☐ Moderately ☐ Quite a bit ☐ Extremely

Can you please comment on **how your family** is/ was affected________________________________

______________________________________________________________________

**15. Can you reflect on how you felt about your son/ daughter moving out of the school system? Perhaps moving out into the community, getting a job, and so forth**

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

Reference Kraemer, B. R., & Blacher, J. (2001).

**16. In thinking about your son/ daughter, please indicate how much you feel HE /SHE is satisfied or dissatisfied with the following, where**

1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4= satisfied and 5 = very satisfied

| | Very dissatisfied | | | | Very satisfied |
|---|---|---|---|---|---|
| (a) to what extent his/ her health needs are catered for? | 1 | 2 | 3 | 4 | 5 |
| (b) His/ her relationship with family members | 1 | 2 | 3 | 4 | 5 |
| (c) His/ her relationships with other people outside the family | 1 | 2 | 3 | 4 | 5 |
| (d) With his/ her daytime activities | 1 | 2 | 3 | 4 | 5 |
| (e) How safe he/ she feels | 1 | 2 | 3 | 4 | 5 |
| (f) His/ her feeling part of the community | 1 | 2 | 3 | 4 | 5 |
| (g) His/ her life as a whole | 1 | 2 | 3 | 4 | 5 |

Acknowledgement- Adaption of Personal Wellbeing Index –Intellectual Disability 3rd Edition. Robert A. Cummins, Anna L.D. Lau 2005

Part 1: S12B-6

# PART 2 - YOUR FAMILY: INSTRUCTIONS

As you are aware, Down syndrome is more than a set of symptoms shown by a particular individual. It can have wide reaching effects on a family including the health of parents, communication between partners, needs for personal support, and stress levels. The questions in Part 2 ask about the experiences of families of young adults with Down syndrome, in order to gain an understanding of how families manage with a son/ daughter with Down syndrome, particularly as they enter adulthood.

We aim to identify areas of family life that are vulnerable to the experience of transition from school to adulthood for young people with Down syndrome, and promote them as being important when policies for the support and care of families with disabled children are developed.

These questions have been included after consultation with parents of children with Down syndrome and other disabilities. The questions have been widely used in research with the general population.

The following questions in Part 2 should be filled out by the MAIN CARER of the individual with Down syndrome, that is the person who provides most of his/her day-to-day care (if your child no longer lives at home with you, these questions should be filled out by the person who was previously the main carer when your son/ daughter lived at home). Please indicate the relationship of the main carer to the child or young adult with Down syndrome:

☐ Mother
☐ Father
☐ Foster Mother
☐ Foster Father
☐ Adoptive Mother
☐ Adoptive Father
☐ Stepmother
☐ Stepfather
☐ Other (please specify)________________

We hope that you will contact us if you have any queries about these questions.

# SECTION 1: FAMILY QUALITY OF LIFE

*This section is about how you feel about your life together as a family. Please consider your family as those people who think of themselves as part of your family and who support and care for each other on a regular basis. Please think about your family life over the past 12 months.*

Please circle the response that best describes your level of satisfication. Please answer all questions.

1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4= satisfied and 5 = very satisfied.

| | Very dissatisfied | | | | Very satisfied |
|---|---|---|---|---|---|
| 1. My family enjoys spending time together | 1 | 2 | 3 | 4 | 5 |
| 2. My family members help the children learn to be independent. | 1 | 2 | 3 | 4 | 5 |
| 3. My family has the support we need to relieve stress. | 1 | 2 | 3 | 4 | 5 |
| 4. My family members have friends or others who provide support. | 1 | 2 | 3 | 4 | 5 |
| 5. My family members help the children with schoolwork and activities. | 1 | 2 | 3 | 4 | 5 |
| 6. My family members have transportation to get to the places they need to be. | 1 | 2 | 3 | 4 | 5 |
| 7. My family members talk openly with each other. | 1 | 2 | 3 | 4 | 5 |
| 8. My family members teach the children how to get along with others. | 1 | 2 | 3 | 4 | 5 |
| 9. My family members have some time to pursue our own interests. | 1 | 2 | 3 | 4 | 5 |
| 10. Our family solves problems together. | 1 | 2 | 3 | 4 | 5 |
| 11. My family members support each other to accomplish goals. | 1 | 2 | 3 | 4 | 5 |
| 12. My family members show that they love and care for each other. | 1 | 2 | 3 | 4 | 5 |
| 13. My family has outside help available to us to take care of special needs of all family members. | 1 | 2 | 3 | 4 | 5 |
| 14. Adults in our family teach the children to make good decisions. | 1 | 2 | 3 | 4 | 5 |
| 15. My family gets medical care when needed. | 1 | 2 | 3 | 4 | 5 |
| 16. My family has a way to take care of our expenses. | 1 | 2 | 3 | 4 | 5 |
| 17. Adults in my family know other people in the children's lives (friends, teachers, etc.). | 1 | 2 | 3 | 4 | 5 |
| 18. My family is able to handle life's ups and downs. | 1 | 2 | 3 | 4 | 5 |
| 19. Adults in my family have time to take care of the individual needs of every child. | 1 | 2 | 3 | 4 | 5 |
| 20. My family gets dental care when needed. | 1 | 2 | 3 | 4 | 5 |
| 21. My family feels safe at home, work, school, and in our neighborhood. | 1 | 2 | 3 | 4 | 5 |
| 22. My family member with a disability has support to accomplish goals at school or at workplace. | 1 | 2 | 3 | 4 | 5 |
| 23. My family member with a disability has support to accomplish goals at home. | 1 | 2 | 3 | 4 | 5 |
| 24. My family member with a disability has support to make friends. | 1 | 2 | 3 | 4 | 5 |
| 25. My family has a good relationship with the service providers who work with our family member with a disability. | 1 | 2 | 3 | 4 | 5 |

*Reference: Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006).*

# SECTION 2: INFORMAL ASSISTANCE NEEDS

*Listed below are 12 different types of assistance which people sometimes find helpful.*
*These questions ask you to indicate how much you would **like help** in these areas.*
Please circle the response that best describes your needs. Please answer all questions.

| **To what extent do you feel a need for any of the following types of help or assistance?** | **Never** | **Once in a while** | **Sometimes** | **Often** | **Quite often** |
|---|---|---|---|---|---|
| 1. Someone to talk to about things that worry you | 1 | 2 | 3 | 4 | 5 |
| 2. Someone to help take care of your child | 1 | 2 | 3 | 4 | 5 |
| 3. Someone to talk to when you have questions about raising your child | 1 | 2 | 3 | 4 | 5 |
| 4. Someone who loans you money when you need it | 1 | 2 | 3 | 4 | 5 |
| 5. Someone to encourage or keep you going when things seem hard | 1 | 2 | 3 | 4 | 5 |
| 6. Someone who accepts your child regardless of how s/he acts | 1 | 2 | 3 | 4 | 5 |
| 7. Someone to help with household chores | 1 | 2 | 3 | 4 | 5 |
| 8. Someone to relax or joke with | 1 | 2 | 3 | 4 | 5 |
| 9. Someone to do things with your child | 1 | 2 | 3 | 4 | 5 |
| 10. Someone to provide you or your child with transportation | 1 | 2 | 3 | 4 | 5 |
| 11. Someone to deal with agencies or individuals when you cannot | 1 | 2 | 3 | 4 | 5 |
| 12. Someone who tells you about services for your child or family | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Dunst and Trivette, 1988.*

The following question relates to the availability of support and assistance in your NEIGHBOURHOOD.

**13. Do you know any of your neighbours well enough to do any of the following?**

| Please tick yes or no for all statements. | **Yes** | **No** |
|---|---|---|
| have a child minded for an hour in an emergency? | ☐ | ☐ |
| have a child minded regularly? | ☐ | ☐ |
| borrow $5 until you go to the bank? | ☐ | ☐ |
| borrow something else? | ☐ | ☐ |
| water the garden for you if you are away? | ☐ | ☐ |
| feed your pets if you are away? | ☐ | ☐ |
| have a talk with you if you are feeling down? | ☐ | ☐ |
| get small items of shopping if you are ill? | ☐ | ☐ |
| keep an eye on your home if you go away? | ☐ | ☐ |
| I live in area where there are no neighbours nearby | ☐ | ☐ |
| I have recently moved house | ☐ | ☐ |

*Acknowledgement: Zubrick, Williams, Silburn and Vimpani, 2000.*

# SECTION 3: AVAILABILITY OF TIME

*Caring for a child with Down syndrome may or may not place added demands on a parent's time. The following items ask whether you feel you have enough time to meet the requirements of the family as a whole and also to meet your own individual requirements.*

For each item, please circle the response that best describes how well the requirement is met on a consistent basis in your family (that is, month in and month out).

| **To what extent are the following time resources adequate for you** | **Does not apply** | **Not at all adequate** | **Seldom adequate** | **Sometimes adequate** | **Usually adequate** | **Almost always adequate** |
|---|---|---|---|---|---|---|
| 1. Time to get enough sleep/rest | NA | 1 | 2 | 3 | 4 | 5 |
| 2. Time to be by yourself | NA | 1 | 2 | 3 | 4 | 5 |
| 3. Time for family to be together | NA | 1 | 2 | 3 | 4 | 5 |
| 4. Time to be with child(ren) | NA | 1 | 2 | 3 | 4 | 5 |
| 5. Time to be with your spouse or partner | NA | 1 | 2 | 3 | 4 | 5 |
| 6. Time to be with close friend(s) | NA | 1 | 2 | 3 | 4 | 5 |
| 7. Time to socialise | NA | 1 | 2 | 3 | 4 | 5 |
| 8. Time to keep in shape and look nice | NA | 1 | 2 | 3 | 4 | 5 |
| 9. Time and money for travel/vacation | NA | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Dunst et al, 1988.*

# SECTION 4: AGREEMENT WITH YOUR PARTNER

*We are interested in the extent of agreement between you and your partner.*
*"Partner" is the person with whom you have the most significant relationship.*
*For example, partner could be a spouse, girl/boyfriend, parent or sibling.*

Do you have a partner at present, ☐ Yes ☐ No
if not, please skip this section and **go to the Section 5.**

**1. Please indicate the approximate extent of agreement or disagreement between you and your partner for each of the following three items.**

**Please circle the number which best fits your answer.**

| | **Always agree** | **Almost always agree** | **Occasionally disagree** | **Frequently disagree** | **Almost always disagree** | **Always disagree** |
|---|---|---|---|---|---|---|
| 1. Philosophy of life | 5 | 4 | 3 | 2 | 1 | 0 |
| 2. Aims, goals and things believed to be important | 5 | 4 | 3 | 2 | 1 | 0 |
| 3. Amount of time spent together | 5 | 4 | 3 | 2 | 1 | 0 |

**2. How often would you say the following events occur between you and your partner?**

| | **Never** | **Less than once a month** | **Once or twice a month** | **Once or twice a week** | **Once a day** | **More often** |
|---|---|---|---|---|---|---|
| 4. Have a stimulating conversation | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. Calmly discuss something | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. Work together on a project | 0 | 1 | 2 | 3 | 4 | 5 |

**3. The dots on the following line represent different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle <u>the dot</u> which best describes the degree of happiness, all things considered, of your relationship.**

| 0 | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| ● | ● | ● | ● | ● | ● | ● |
| Extremely unhappy | Fairly unhappy | A little unhappy | Happy | Very happy | Extremely happy | Perfect |

*Acknowledgement: Sharpley and Rogers, 1984.*

# SECTION 5: FAMILY AND DOWN SYNDROME

*This section asks about other family members and whether having a child with Down syndrome impacts on the family*

**1. Apart from your child with Down syndrome do you have any other children (including foster, step and/or adopted children)?**

☐ No, **please go to Question 4.**
☐ Yes, please provide us with some information which may be helpful to Down syndrome research:

| Relationship to child with Down syndrome | Date of birth | Gender | Serious medical conditions or disabilities? (Please list) | Lives with child with Down syndrome? |
|---|---|---|---|---|
| **Example answer** | | | | |
| Sister | 20.10.93 | F | None | ☑ Yes ☐ No |
| **Your answer** | | | | |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |
| | | | | ☐ Yes ☐ No |

**2. Do you think there have been benefits to your other children because they have a sibling with Down syndrome?**

☐ No
☐ Yes, please describe the benefits in the following space:

**3. Do you think there have been disadvantages to your other children because they have a sibling with Down syndrome?**

☐ No
☐ Yes, please describe the disadvantages in the following space:

4. **Please describe the impact (if any) of having a child with Down syndrome on family recreational activities.**

________________________________________

________________________________________

________________________________________

________________________________________

5. **Please describe the impact (if any) of Down syndrome on family holidays.**

________________________________________

________________________________________

________________________________________

________________________________________

6. **Please feel free to write any comments about other ways in which having a child with Down syndrome has affected your family.**

________________________________________

________________________________________

________________________________________

________________________________________

# SECTION 6: FAMILY COMMUNICATION

*The following questions ask about aspects of communication between members of your family. We would like to know whether there are changes in the dynamics of families who care for a child with a disability.*

**Please circle the response that best suits your answer.**
"Agree" means that while you do not "strongly agree" with the statement, you would tend to agree more often than disagree.
"Disagree" means that you would tend to disagree more often than you would agree with the statement.

| | Strongly agree | Agree | Disagree | Strongly disagree |
|---|---|---|---|---|
| 1. Planning family activities is difficult because we misunderstand each other | SA | A | D | SD |
| 2. In times of crisis we can turn to each other for support | SA | A | D | SD |
| 3. We cannot talk to each other about sadness we feel | SA | A | D | SD |
| 4. Individuals (in the family) are accepted for what they are | SA | A | D | SD |
| 5. We avoid discussing our fears and concerns | SA | A | D | SD |
| 6. We express feelings to each other | SA | A | D | SD |
| 7. There are lots of bad feelings in our family | SA | A | D | SD |
| 8. We feel accepted for what we are | SA | A | D | SD |
| 9. Making decisions is a problem in our family | SA | A | D | SD |
| 10. We are able to make decisions about how to solve problems | SA | A | D | SD |
| 11. We don't get on well together | SA | A | D | SD |
| 12. We confide in each other | SA | A | D | SD |

*Acknowledgement: Epstein, Baldwin and Bishop, 1983.*

# SECTION 7: SELF ASSESSMENT OF MOOD

*Whilst many things may contribute to the ups and downs in one's life, we would like to know whether your every day moods and feelings are influenced by having a child with Down syndrome*

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week.** There are no right or wrong answers. Do not spend too much time on any statement.

**The rating scale is as follows :**

0 Did not apply to me at all.
1 Applied to me to some degree, or some of the time.
2 Applied to me a considerable degree, or a good part of the time.
3 Applied to me very much, or most of the time.

---

1. I found it hard to wind down. 0 1 2 3
2. I was aware of dryness in my mouth. 0 1 2 3
3. I couldn't seem to experience any positive feelings at all. 0 1 2 3
4. I experienced breathing difficulty (eg. excessively rapid breathing, breathlessness in the absence of physical exertion). 0 1 2 3
5. I found it difficult to work up the initiative to do things. 0 1 2 3
6. I tended to over-react to situations. 0 1 2 3
7. I experienced trembling (eg. in the hands). 0 1 2 3
8. I felt that I was using a lot of nervous energy. 0 1 2 3
9. I was worried about situations in which I might panic and make a fool of myself. 0 1 2 3
10. I felt that I had nothing to look forward to. 0 1 2 3
11. I found myself getting agitated. 0 1 2 3
12. I found it difficult to relax. 0 1 2 3
13. I felt down-hearted and blue. 0 1 2 3
14. I was intolerant of anything that kept me from getting on with what I was doing. 0 1 2 3
15. I felt I was close to panic. 0 1 2 3
16. I was unable to become enthusiastic about anything. 0 1 2 3
17. I felt that I wasn't worth much as a person. 0 1 2 3
18. I felt I was rather touchy. 0 1 2 3
19. I was aware of the action of my heart in the absence of physical exertion (eg. sense of heart rate increase, heart missing a beat). 0 1 2 3
20. I felt scared without any good reason. 0 1 2 3
21. I felt that life was meaningless. 0 1 2 3

*Acknowledgement: Lovibond and Lovibond, 1993.*

# Section 8: Self Assessment of Personal Health

*The state of one's health may be of extra importance for a parent having a son/ daughter with Down syndrome. The following questions ask for your views about your health.*

Answer every question by marking the circle that best fits your answer.
If you are unsure about how to answer a question, please give the best answer you can.

| | Excellent | Very good | Good | Fair | Poor |
|---|---|---|---|---|---|
| **1. In general, would you say your health is:** | ○ | ○ | ○ | ○ | ○ |

The following questions are about activities you might do during a typical day.
Does your health *now* limit you in these activities? If so, how much?

| | Yes, limited a lot | Yes, limited a little | No, not limited at all |
|---|---|---|---|
| **2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:** | ○ | ○ | ○ |
| **3. Climbing several flights of stairs:** | ○ | ○ | ○ |

During the past *4 weeks*, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| **4. Accomplished less than you would like:** | ○ | ○ | ○ | ○ | ○ |
| **5. Were limited in the kind of work or other activities:** | ○ | ○ | ○ | ○ | ○ |

During the past *4 weeks*, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| **6. Accomplished less than you would like:** | ○ | ○ | ○ | ○ | ○ |
| **7. Didn't do work or other activities as carefully as usual:** | ○ | ○ | ○ | ○ | ○ |

**8. During the past *4 weeks*, how much did pain interfere with your normal work (including both work outside the home and housework)?**

| Not at all | A little bit | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ |

These questions are about how you feel and how things have been with you during the past *4 weeks*. For each question, please give the one answer that comes closest to the way you have been feeling.

| How much of the time during the past 4 weeks..... | **All of the time** | **Most of the time** | **Some of the time** | **A little of the time** | **None of the time** |
|---|---|---|---|---|---|
| **9. Have you felt calm and peaceful?** | ○ | ○ | ○ | ○ | ○ |
| **10. Did you have a lot of energy?** | ○ | ○ | ○ | ○ | ○ |
| **11. Have you felt downhearted and blue?** | ○ | ○ | ○ | ○ | ○ |

**12. During the past *4 weeks*, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**

| **All of the time** | **Most of the time** | **Some of the time** | **A little of the time** | **None of the time** |
|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ |

**13. Please discuss the impact that having a child with Down syndrome has had on the health of the family. This may be mental, physical or any other aspect of health.**

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

*Acknowledgement: Ware, Kosinski and Keller, 1996.*

# SECTION 9: FAMILY AND COMMUNITY SUPPORT

*Listed below are people and groups that are often helpful to members of a family raising a child with Down syndrome. The following questions ask you to indicate **how helpful** each source is to your family.*

| How helpful has each of the following been to you in terms of raising your child with Down syndrome? | Does not apply | Not at all helpful | Sometimes helpful | Generally helpful | Very helpful | Almost always helpful |
|---|---|---|---|---|---|---|
| 1. My parents | NA | 1 | 2 | 3 | 4 | 5 |
| 2. My spouse or partner's parents | NA | 1 | 2 | 3 | 4 | 5 |
| 3. My relatives | NA | 1 | 2 | 3 | 4 | 5 |
| 4. My spouse or partner's relatives | NA | 1 | 2 | 3 | 4 | 5 |
| 5. Spouse or partner | NA | 1 | 2 | 3 | 4 | 5 |
| 6. My friends | NA | 1 | 2 | 3 | 4 | 5 |
| 7. My spouse or partner's friends | NA | 1 | 2 | 3 | 4 | 5 |
| 8. My own children | NA | 1 | 2 | 3 | 4 | 5 |
| 9. Other parents | NA | 1 | 2 | 3 | 4 | 5 |
| 10. Co-workers | NA | 1 | 2 | 3 | 4 | 5 |
| 11. Parent groups | NA | 1 | 2 | 3 | 4 | 5 |
| 12. Social groups / clubs | NA | 1 | 2 | 3 | 4 | 5 |
| 13. Members of church or religious group / minister or leader | NA | 1 | 2 | 3 | 4 | 5 |
| 14. My family or child's physician | NA | 1 | 2 | 3 | 4 | 5 |
| 15. Early childhood intervention program | NA | 1 | 2 | 3 | 4 | 5 |
| 16. Play group / school / day-care centre | NA | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Dunst, Jenkins and Trivette, 1988.*

# GLOSSARY OF TERMS

**Atlantoaxial (AA) instability -** Increased mobility of the neck joints.

**Atrial septal defect -** A congenital heart defect where an abnormal opening exists in the muscular wall between the left and right atria of the heart.

**Congenital -** Present at birth.

**Duodenal atresia -** A blockage or obstruction of the first part of the small intestine.

**Hirschsprung disease -** A congenital condition which results in an enlarged and poorly functioning colon.

**Scoliosis -** A congenital lateral curvature of the spine.

**Tetralogy of Fallot -** A congenital heart defect which results in a blue baby at birth due to a lack of oxygen.

**Ventricular septal defect -** A congenital heart defect where an abnormal opening exists in the muscular wall between the left and right ventricles of the heart.

# QUESTIONNAIRE FEEDBACK

**1. Did you find any of the questions confusing or difficult to answer?**

☐ No - **please go to Question 2.**
☐ Yes - please describe which questions in the space below:

**2. Did you find any of the questions upsetting?**

☐ No - **please go to Question 3.**
☐ Yes - please describe which questions in the space below:

**3. Are there any other questions or topics you think we should have included?**

☐ No
☐ Yes - please make any suggestions in the space below:

**4. How long did it take you to complete the questionnaire?**____________________

**5. Did you hear about this study before receiving this questionnaire in the mail? If yes, how did you hear about it?**

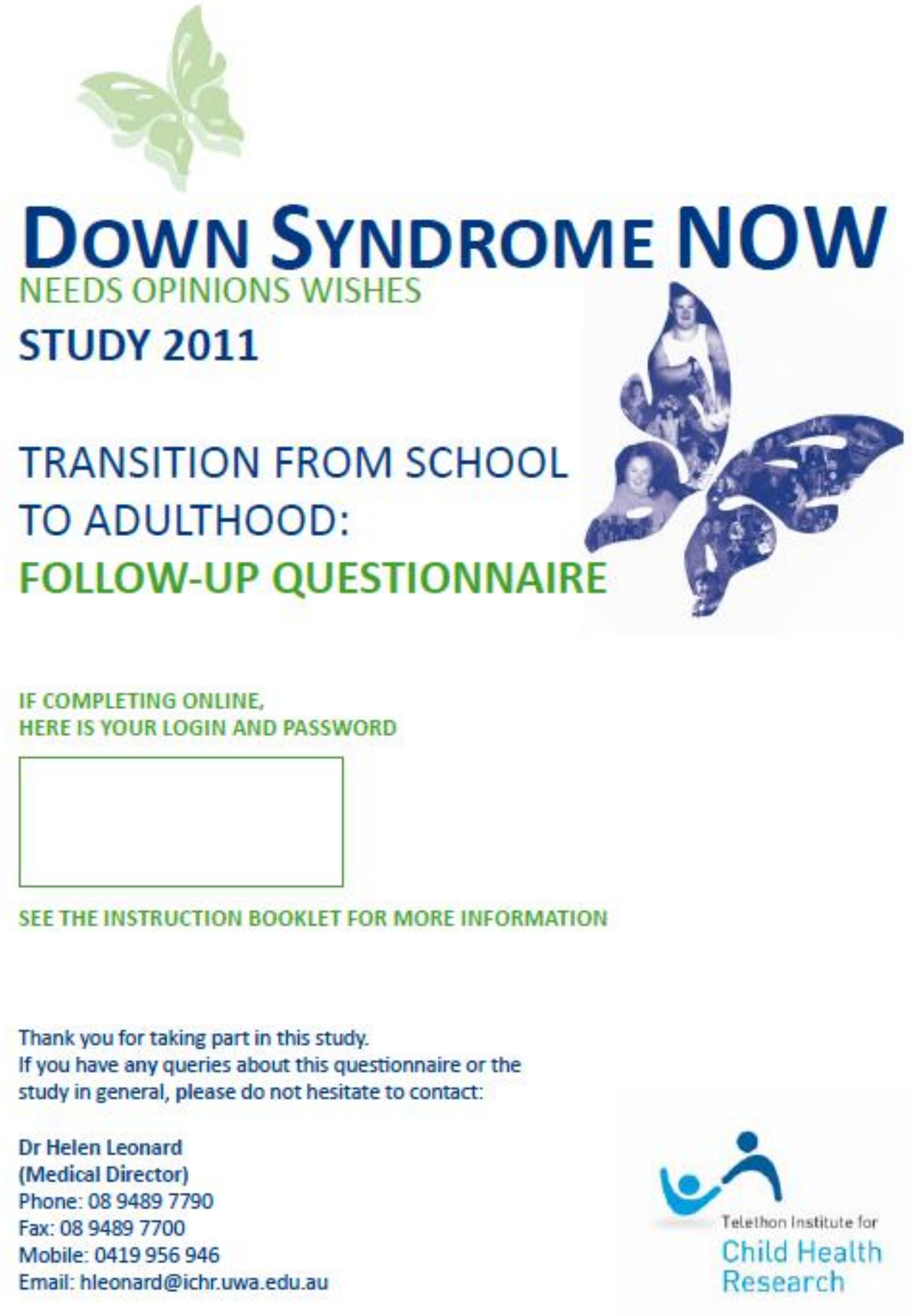
**If you have any further comments about this questionnaire, this research or anything else that you would like to tell us about, please make them in the space below:**

**Thank you so much for taking the time to complete this questionnaire.**
**We appreciate your contribution to Down syndrome research.**

Please return this questionnaire <u>and</u> the consent form
in the reply paid envelope provided to:

Down Syndrome Transition Study
Telethon Institute for Child Health Research
PO Box 855
WEST PERTH WA 6872

Appendix D: 2011 Down syndrome 'NOW' questionnaire



# DOWN SYNDROME NOW

NEEDS OPINIONS WISHES

## STUDY 2011

## TRANSITION FROM SCHOOL TO ADULTHOOD: FOLLOW-UP QUESTIONNAIRE

IF COMPLETING ONLINE,
HERE IS YOUR LOGIN AND PASSWORD

SEE THE INSTRUCTION BOOKLET FOR MORE INFORMATION

Thank you for taking part in this study.
If you have any queries about this questionnaire or the study in general, please do not hesitate to contact:

**Dr Helen Leonard**
**(Medical Director)**
Phone: 08 9489 7790
Fax: 08 9489 7700
Mobile: 0419 956 946
Email: hleonard@ichr.uwa.edu.au

Telethon Institute for
Child Health
Research

## Privacy Statement

All research projects undertaken by the Institute have been submitted to and approved by one or more State ethics committee(s). The researchers conducting the project then obtain your consent to supply us with any personal information.

We use your personal information to:

a) Process research project results looking for causes or ways of preventing particular childhood conditions and/or providing the optimal treatment and support for people with those conditions.

b) Perform medical research and statistical analyses into the general health of populations to inform health providers and assist in government policy and planning.

When we receive completed questionnaires or other information from you, we remove any identifying data such as your name, address and telephone number. Identifying material is kept separately from your data. Both are stored in electronic and paper forms. Electronic data are kept on a secure network and protected by passwords that only members of the research team have knowledge of. Paper questionnaires are stored in locked cabinets in locked rooms in which members of the research team work.

Your information is shared between clinicians and researchers working on the project. At any time you can request to review any information that you have given to us.

## Acknowledgements

We would like to acknowledge the Australian Research Council for their financial support. We also acknowledge the support of the Disability Services Commission of Western Australia, the WA Department of Education and Training, Down Syndrome WA and Edge Employment for their support and collaboration on this project.

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# PART 1

# YOUR SON/DAUGHTER

**Instructions**
This questionnaire is a follow-up to the first Transition Questionnaire sent out in 2009/ 2010. If you participated in the previous questionnaire we thank you for your important contribution. As your son's / daughter's activities, health or functioning may have changed, or your own situation may be different, we ask that you kindly take the time to once again complete this questionnaire.

THIS QUESTIONNAIRE IS ABLE TO BE COMPLETED ONLINE.
YOUR LOGIN AND PASSWORD ARE ON THE FRONT COVER AND AN INSTRUCTION SHEET IS ENCLOSED.

The questions in the first part of this booklet relate to your son or daughter with Down syndrome. The information you provide will help explain what happens to individuals with Down syndrome and their families over time and why the outcomes may differ as the young people move from adolescence to adulthood.

Please note that you are not required to fill out the entire questionnaire in one sitting - you may wish to complete it over a few separate occasions.

Even though your young adult may not be living at home with you, we would still like you to fill out the questionnaire as your perspective on the issues raised is important. Parents and other people involved in providing care and support to people with Down syndrome have advised and guided us in the development of the questionnaire.

The questions ask you to either mark a box, fill in a table or write in a space. If there are any questions which seem unclear or are difficult to understand, please do not hesitate to contact Dr Helen Leonard (details are on the cover page of this booklet), who will be happy to help you.

**We are very appreciative of the time that you are giving to complete this questionnaire. Your contribution to this research will be extremely valuable in identifying the major issues currently facing young adults with Down syndrome and their families. We hope this research will lead to strategies and policies that will improve future outcomes as young people with Down syndrome transition from school to adulthood.**

# SECTION 1: PARENT INFORMATION

**These first questions are to collect some background information about the parents of the young adult with Down syndrome.**

**1. Please indicate your relationship to the young adult who has Down syndrome.**
*Note: If more than one person is completing this questionnaire please tick all boxes which apply.*

☐ Natural mother
☐ Natural father
☐ Foster mother
☐ Foster father
☐ Other (please specify) ______________________________

☐ Adoptive mother
☐ Adoptive father
☐ Stepmother
☐ Stepfather

**2. Mother's date of birth:** D D / M M / Y Y Y Y

**3. Father's date of birth:** D D / M M / Y Y Y Y

**4. Marital status:**
☐ Single ☐ Married ☐ De facto ☐ Never married ☐ Widowed ☐ Divorced ☐ Separated

**5. Please provide your postcode**_________

**6. Please provide your address (optional):**________________________________________

________________________________________________________________

**The following questions are about the MOTHER of the young person with Down syndrome**

**7. What is the highest qualification that she has completed?**

☐ Primary school
☐ Completed high school (Year 12 or equivalent)
☐ Advanced diploma
☐ Graduate diploma or certificate

☐ Some high school
☐ Trade or technical qualification (Cert level)
☐ Bachelor degree
☐ Postgraduate degree (Masters or PhD)

**8. Which of the following best describes her current work status?**
☐ Not working due to her child's disability
☐ Not working for other reasons
☐ Fulltime homemaker
☐ Looking for work outside the home
☐ Working full-time (either outside the home or at a home-based business)
☐ Working part-time

**Please provide the following information for all jobs currently held:**

Job title:________________________________________ Hours worked per week:________

Main tasks:____________________________________________________________

Job title:________________________________________ Hours worked per week:________

Main tasks:____________________________________________________________

**The following questions are about the FATHER of the young person with Down syndrome**

**9. What is the highest qualification that he has completed?**

☐ Primary school
☐ Completed high school (Year 12 or equivalent)
☐ Advanced diploma
☐ Graduate diploma or certificate
☐ Some high school
☐ Trade or technical qualification (Cert level)
☐ Bachelor degree
☐ Postgraduate degree (Masters or PhD)

**10. Which of the following best describes his current work status?**

☐ Not working due to his child's disability
☐ Not working for other reasons
☐ Fulltime homemaker
☐ Looking for work outside the home
☐ Working full-time (either outside the home or at a home-based business)
☐ Working part-time

**Please provide the following information for all jobs currently held:**

Job title:________________________________________ Hours worked per week:________

Main tasks:____________________________________________________________

Job title:________________________________________ Hours worked per week:________

Main tasks:____________________________________________________________

**The following questions are about your son or daughter with Down syndrome**

**11. What is your son's/daughter's date of birth:** D D / M M / Y Y Y Y

**12. What is your child's gender?**

☐ Male
☐ Female

# SECTION 2: MEDICAL CONDITIONS

This section asks about health and medical conditions of your son/daughter, as it is important to understand their general wellbeing and how this may impact on their daily life.

Case example:

| Condition | Does your son / daughter currently have this condition | To what extent does this condition impact on daily life? | | | | If any impact, please describe:<br>1. How the condition is impacting on daily life?<br>2. How it is managed? |
|---|---|---|---|---|---|---|
| | | None | Minor | Moderate | Major | |
| **EAR & HEARING** | | | | | | |
| Hearing loss | ☑ Yes ☐ No | | ✓ | | | 1. She has difficulty hearing conversation when it's noisy<br>2. Wears hearing aids |
| Glue ear, otitis media | ☑ Yes ☐ No | | | ✓ | | 1. Painful<br>2. Had grommets |

Please complete for your young adult.

| Condition | Does your son / daughter currently have this condition | To what extent does this condition impact on daily life? | | | | If any impact, please describe:<br>1. How the condition is impacting on daily life?<br>2. How it is managed? |
|---|---|---|---|---|---|---|
| | | None | Minor | Moderate | Major | |
| **HEART** | | | | | | |
| Congenital heart disease | ☐ Yes ☐ No | | | | | |
| Cardiomyopathy (disease of the heart muscle) | ☐ Yes ☐ No | | | | | |
| Other heart (please describe) | | | | | | |
| **BOWEL** | | | | | | |
| Constipation | ☐ Yes ☐ No | | | | | |
| Coeliac disease | ☐ Yes ☐ No | | | | | |
| Other bowel (please describe) | | | | | | |

| Condition | Does your son / daughter currently have this condition | To what extent does this condition impact on daily life? None | Minor | Moderate | Major | If any impact, please describe:<br>1. How the condition is impacting on daily life?<br>2. How it is managed? |
|---|---|---|---|---|---|---|
| **EAR & HEARING** | | | | | | |
| Hearing loss | ☐ Yes ☐ No | | | | | |
| Glue ear, otitis media | ☐ Yes ☐ No | | | | | |
| Other ear (please describe) | | | | | | |
| **EYE & VISION** | | | | | | |
| Short-sightedness | ☐ Yes ☐ No | | | | | |
| Long-sightedness | ☐ Yes ☐ No | | | | | |
| Astigmatism (or other refractive errors) | ☐ Yes ☐ No | | | | | |
| Strabismus | ☐ Yes ☐ No | | | | | |
| Other eye (eg. cataracts) (please describe) | | | | | | |
| **THYROID** | | | | | | |
| Hypothyroidism (underactive) | ☐ Yes ☐ No | | | | | |
| Hyperthyroidism (overactive) | ☐ Yes ☐ No | | | | | |
| **MENSTRUAL PROBLEMS** | | | | | | |
| eg. heavy or painful periods | ☐ Yes ☐ No | | | | | |
| **DIABETES** | | | | | | |
| Type 1 (juvenile onset) | ☐ Yes ☐ No | | | | | |
| Type 2 (mature/lifestyle onset) | ☐ Yes ☐ No | | | | | |
| **BODY WEIGHT** | | | | | | |
| Obesity or overweight | ☐ Yes ☐ No | | | | | |
| Underweight | ☐ Yes ☐ No | | | | | |

| Condition | Does your son / daughter currently have this condition | To what extent does this condition impact on daily life? | | | | If any impact, please describe:<br>1. How the condition is impacting on daily life?<br>2. How it is managed? |
|---|---|---|---|---|---|---|
| | | None | Minor | Moderate | Major | |
| **MUSCLE & BONE** | | | | | | |
| Foot problems (eg. flat foot) | ☐ Yes ☐ No | | | | | |
| Atlantoaxial instability | ☐ Yes ☐ No | | | | | |
| Scoliosis | ☐ Yes ☐ No | | | | | |
| Arthritis | ☐ Yes ☐ No | | | | | |
| Other muscle/bone (please describe) | | | | | | |
| **RESPIRATORY** | | | | | | |
| Sleep apnoea | ☐ Yes ☐ No | | | | | |
| Asthma | ☐ Yes ☐ No | | | | | |
| Other respiratory (please describe) | | | | | | |
| **SKIN** | | | | | | |
| Psoriasis | ☐ Yes ☐ No | | | | | |
| Acne | ☐ Yes ☐ No | | | | | |
| Fungal infections | ☐ Yes ☐ No | | | | | |
| **MENTAL HEALTH** | | | | | | |
| Anxiety | ☐ Yes ☐ No | | | | | |
| Depression | ☐ Yes ☐ No | | | | | |
| Other mental health (please describe) | | | | | | |
| **OTHER MAJOR CONDITIONS** | | | | | | |
| eg. leukaemia, epilepsy, gynaecological (please describe) | | | | | | |

# SECTION 3: MEDICAL CARE, SERVICES AND ILLNESS

It is important to know about the illnesses experienced by young adults with Down syndrome as this may impact on how much they are able to work. It is also important to know whether your son's/daughter's medical care needs are being met.

**1. Has your son/daughter had any illnesses in the last 12 months?**

| Condition | | Number of episodes |
|---|---|---|
| Colds or flu | ☐ Yes ☐ No | |
| Bronchitis / Pneumonia | ☐ Yes ☐ No | |
| Ear infection | ☐ Yes ☐ No | |
| Other- please describe | ☐ Yes ☐ No | |

**2. Has your son/daughter visited any medical practitioners/specialists in the last 12 months?**

| Type of practitioner | Has your son / daughter visited this medical professional in the last 12 months? | Number of visits |
|---|---|---|
| **DOCTOR** | | |
| GP | ☐ Yes ☐ No | |
| Other specialist (please describe) | ☐ Yes ☐ No | |
| **MENTAL HEALTH PROFESSIONAL** | | |
| Doctor | ☐ Yes ☐ No | |
| Psychologist | ☐ Yes ☐ No | |
| **ALLIED HEALTH PROFESSIONAL** | | |
| Please list, eg. physiotherapist | ☐ Yes ☐ No | |
| **ALTERNATIVE THERAPISTS** | | |
| Please list, eg. naturopath | ☐ Yes ☐ No | |

**3. Has your son/daughter had any medical care that involved day admissions or overnight stays in hospital IN THE LAST 12 MONTHS?**

| Hospital stay | Reason for admission |
|---|---|
| 1 | |
| 2 | |
| 3 | |

**4. Please rate to what extent the medical care needs of your son/ daughter have been met IN THE LAST 12 MONTHS?**

| Very great extent | Great extent | Fairly great extent | Moderate extent | Small extent | Very small extent | Not at all | Does not apply |
|---|---|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Please add any comments : ____________________________________________

____________________________________________

____________________________________________

**5. What is your son's/daughter's current height and weight.**

Height____________________cm or ____________________feet ____________________inches

Weight____________________kg or ____________________stone ____________________lbs

# SECTION 4: NUTRITION

**This section asks about your son's / daughter's food patterns, behaviours and physical activity. Nutrition and physical activity are very important to health and well-being for your son or daughter.**

Please answer the following questions exploring some of the factors influencing what your son or daughter eats now, and what they ate as an infant. Please also answer the questions on physical activity so we can find out how much and in what types of activities your son or daughter participates.

**Please circle the appropriate answer.**

| | Never | Seldom | Half of the Time | Most of the Time | Always |
|---|---|---|---|---|---|
| When your son/daughter is at home, how often are you responsible for preparing his/her meals? | 1 | 2 | 3 | 4 | 5 |
| How often are you responsible for deciding what your son's/daughter's portion sizes are? | 1 | 2 | 3 | 4 | 5 |
| How often are you responsible for deciding if your son/daughter has eaten the right kind of foods? | 1 | 2 | 3 | 4 | 5 |

| | Markedly underweight | Underweight | Normal | Overweight | Markedly overweight |
|---|---|---|---|---|---|
| What was your weight in childhood? | 1 | 2 | 3 | 4 | 5 |
| What was your weight in adolescence? | 1 | 2 | 3 | 4 | 5 |
| What was your weight in your 20's? | 1 | 2 | 3 | 4 | 5 |
| What is your present weight? | 1 | 2 | 3 | 4 | 5 |
| What was your son's/daughter's weight during their first year of life? | 1 | 2 | 3 | 4 | 5 |
| What was your son's/daughter's weight as a toddler? | 1 | 2 | 3 | 4 | 5 |
| What was your son's/daughter's weight as a pre-schooler? | 1 | 2 | 3 | 4 | 5 |
| What was your son's/daughter's weight in primary school? | 1 | 2 | 3 | 4 | 5 |
| What was your son's/daughter's weight in secondary school? | 1 | 2 | 3 | 4 | 5 |
| What was your son's/daughter's weight post secondary school? | 1 | 2 | 3 | 4 | 5 |

| | Unconcerned | A little concerned | Concerned | Fairly concerned | Very concerned |
|---|---|---|---|---|---|
| How concerned are you about your son/daughter eating too much when you are not around them? | 1 | 2 | 3 | 4 | 5 |
| How concerned are you about your son/daughter having to diet to maintain a desirable weight? | 1 | 2 | 3 | 4 | 5 |
| How concerned are you about your son/daughter becoming overweight? | 1 | 2 | 3 | 4 | 5 |

| | Disagree | Slightly disagree | Neutral | Slightly agree | Agree |
|---|---|---|---|---|---|
| I have to watch out my son/daughter does not eat too many sweet foods (lollies, ice-cream, cakes, biscuits). | 1 | 2 | 3 | 4 | 5 |
| I have to watch out that my son/daughter does not eat too many high fat foods. | 1 | 2 | 3 | 4 | 5 |
| I have to watch out that my son/daughter does not eat too many favourite foods. | 1 | 2 | 3 | 4 | 5 |
| I intentionally keep some foods out of my son's/daughter's reach. | 1 | 2 | 3 | 4 | 5 |
| I offer sweet foods (lollies, ice-cream, cakes, biscuits) to my son/ daughter as a reward for good behaviour. | 1 | 2 | 3 | 4 | 5 |
| I offer my son/daughter their favourite foods in exchange for good behaviour. | 1 | 2 | 3 | 4 | 5 |
| If I did not guide or regulate my son's/daughter's eating, he/she would eat too much of their favourite foods. | 1 | 2 | 3 | 4 | 5 |
| My son/daughter should always eat all of the food on their plate. | 1 | 2 | 3 | 4 | 5 |
| I have to be especially careful to make sure my son/daughter eats enough. | 1 | 2 | 3 | 4 | 5 |
| If my son/daughter indicates they are not hungry I try to get them to eat anyway. | 1 | 2 | 3 | 4 | 5 |
| If I did not guide or regulate my son's/daughter's eating, he/she would eat much less than he/she should. | 1 | 2 | 3 | 4 | 5 |

| | Never | Rarely | Sometimes | Often | Always |
|---|---|---|---|---|---|
| How often do you keep track of the sweet foods (lollies, ice-cream, cakes, biscuits) your son/daughter eats? | 1 | 2 | 3 | 4 | 5 |
| How often do you keep track of the savoury snacks (eg. potato chips, corn chips) your son/daughter eats? | 1 | 2 | 3 | 4 | 5 |
| How often do you keep track of the high-fat foods that your son/ daughter eats? | 1 | 2 | 3 | 4 | 5 |
| How often do you keep track of the high-sugar beverages (eg. lemonade, Cola) that your son/daughter drinks? | 1 | 2 | 3 | 4 | 5 |
| How often do you keep track of alcoholic beverages that your son/ daughter drinks? | 1 | 2 | 3 | 4 | 5 |

*Birch, L.L., Fisher, J.O., Grimm-Thomas, K., Markey, C.N., Sawyer, R., & Johnson, S.L. (2001). Confirmatory factor analysis of the Child Feeding Questionnaire: a measure of parental attitudes, beliefs and practices about child feeding and obesity proneness. Appetite 36, 201-210. doi:10.1006/appe.2001.0398*

## Food Behaviours

1. **Which one of the following describes how your son/daughter eats their main meal of the day.**
   - ☐ Eating alone at the dining table
   - ☐ Eating with one or more other people at the dining table
   - ☐ Eating alone sitting on the couch
   - ☐ Eating with one or more other people sitting on the couch
   - ☐ Other ________________________________________

2. **How often does your son/daughter eat fast food?**
   - ☐ Daily
   - ☐ 4-6 times per week
   - ☐ 2-3 times per week
   - ☐ Once or less than once a week
   - ☐ Twice a month
   - ☐ Once or less than once a month

## Infant Feeding Questions - It would be valuable to have some information about your son's/daughter's earliest nutrition.

1. **How did you feed your son/daughter when newborn?**
   - ☐ Exclusive breastfeeding (no other non-human milk or water)
   - ☐ Infant formula/artificial milk feeding only
   - ☐ Mix of breastfeeding and infant formula

If you exclusively breastfed, what age was your son/daughter when a food or liquid other than breastmilk (including water or infant formula) was introduced?

________________________________________

**2. At what age did you introduce solid food other than breastmilk or formula to your son/daughter?**
**What food was this?**

________________________________________

**3. If you breastfed (either exclusively or partially), how long did you breastfeed your son/daughter?**

________________________________________

**4. Did you experience any difficulties breastfeeding your son/daughter?**

________________________________________

**5. If yes, what difficulties did you experience?**

________________________________________

**6. What (if any) resources or organisations did you use for assistance with feeding your baby son/daughter?**

________________________________________

**7. What (if any) resources or organisations would have been useful to provide you with assistance with feeding your baby son/daughter?**

---

## Physical Activity

**8. Thinking about the last 7 days, on how many days was your son/daughter physically active for 60 minutes or more?** (This can be accumulative over the day, not necessarily all at once).

- ☐ 0 days
- ☐ 1-2 days
- ☐ 3-4 days
- ☐ 5-6 days
- ☐ 7 days

**9. Thinking about the last 7 days, in what types of moderate or vigorous physical activities has your son/ daughter participated?**

| **Activity** | **How much time (minutes) did your son/daughter participate for?** |
|---|---|
| ☐ Jogging/Running | |
| ☐ Swimming | |
| ☐ Gym | |
| ☐ Dancing | |
| ☐ Basketball | |
| ☐ Netball | |
| ☐ Movement based video games | |
| ☐ Bike riding | |
| ☐ Play with pets | |
| ☐ Physical Education Class | |
| ☐ Walking/Riding bike to and from school | |
| ☐ Other, please specify | |

**10. Over the course of a usual 24 hour day how many hours does your son/daughter spend sitting/ reclining/lying down? (not including sleeping)**

---

**11. Apart from sleeping, which other activities does your son/daughter participate in when sitting, reclining or lying down?**

---

*Adapted from: Martin, K., Rosenberg, M., Miller, M., French, S., McCormack, G., Bull, F., Giles-Corti, B., & Pratt, S. (2008). Move and munch final report. Trends in physical activity, nutrition and body size in Western Australian children and adolescents: The Child and Adolescent Physical Activity and Nutrition Survey (CAPANS).*

Part 1: S4-4

# SECTION 5: EVERYDAY FUNCTIONING

**Please tick the box that best describes YOUR SON's/ DAUGHTER's BEST level of functioning**

## ADDITIONAL CONDITIONS

**1. Vision (tick ONE only)**

☐ Normal vision (include glasses)
☐ Partial sight - problems in mobility
☐ Blind for all practical purposes

**2. Hearing (tick ONE only)**

☐ Normal hearing (including deafness in one ear)
☐ Partial hearing; hearing aid prescribed
☐ Profoundly deaf - only residual hearing

**3. Epilepsy (tick ONE only)**

☐ No fits - no medication
☐ Has or had fits; taking medication to control fits, not real problem at present
☐ Has or had fits; taking medication to control fits, recurring problem at present

## COMMUNICATION SKILLS

**4. Instructions (tick ONE only)**

☐ Can remember to carry out a sequence of instructions eg. a shopping list or directions to a place
☐ Can remember instructions and carry out later, eg. a message from work
☐ Follows a simple instruction that can be carried out there and then eg. "switch on the light"
☐ No response when talked to, except to own name

**5. Communication - Speech (tick ONE only)**

☐ Speaks well - intelligible to all; uses appropriate language; able to give accurate information
☐ Some difficulty in speaking - lack of clarity or fluency (e.g may tend to stammer), but language appropriate
☐ Difficulty in speech – only intelligible to those who know him/her well
☐ Does not use speech to communicate

Comments:______________________________________________________________

**If your child is verbal, please go to Q7.**

**6. Nonverbal Communication - eg. gestures, signs, Compic, assisted communication devices (Tick ONE only)**

☐ Communicates well nonverbally
☐ Some difficulty in nonverbal communication
☐ Unable to communicate nonverbally

Please describe method/s of communication used______________________________

## SELF-CARE SKILLS

**7. Eating (Tick ONE only)**

☐ Feeds self and can manage all activities at table with no problem
☐ Feeds self and can manage most activities (eg. cutting meat) but needs some guidance/ help
☐ Feeds self completely but needs help in seasoning foods, cutting meat etc
☐ Needs to be fed or if alone is a messy feeder

**8. Personal Needs (Tick ONE only)**

☐ Can look after his/her personal needs completely independently - cleanliness, toilet, dressing and chooses appropriate clothes
☐ Generally looks after personal needs but requires checking and reminding
☐ Has to be helped to wash, dress etc
☐ Dependent on other persons for all personal needs

**9. Mobility (Tick ONE only)**

☐ Able to walk, run and climb stairs with no difficulty
☐ Able to walk fair distances (around one kilometre) but finds running and climbing stairs difficult
☐ Can walk only short distances; tires easily
☐ Unable to walk alone

**10. Use of Hands (Tick ONE only)**

☐ Fully competent use of hands and fingers - can hit a nail with a hammer, thread needle, use tin opener
☐ Manages most day-to-day activities involving hands, doing up buttons, using knife and fork
☐ Slow and rather clumsy in using hands but manages some day-today activities
☐ Only capable of very basic hand skills or not at all

**11. Around the House (Tick ONE only)**

☐ Capable of doing most jobs around the house without supervision - makes bed, washes and dries dishes, cleans the floor etc
☐ Attempts most jobs but needs supervision and help to complete the job properly
☐ Able to do simple repetitive jobs - setting the table, dries dishes
☐ Attempts these simple jobs but cannot do them properly
☐ Unable to do any household jobs

**12. Preparing Food (Tick ONE only)**

☐ Can prepare an adequate variety of meals without supervision
☐ Prepares simple hot food without supervision - makes eggs, warms soup
☐ Makes up food which does not require cooking or with which he/she is familiar - cereals and sandwiches
☐ With supervision, can prepare simple foods
☐ Needs all food prepared for him/her

## COMMUNITY SKILLS

**13. Reading (Tick ONE only)**

☐ Can read and follow a series of written instructions, eg. directions on a packet of food, recipes
☐ Can read and act appropriately to signs giving directions in shops or in the streets
☐ Can recognise own name written down
☐ Can recognise and pick out around six different labels on tins and boxes of foods, eg. cereals, washing powders

**14. Writing (Tick ONE only)**

☐ Has good writing skills, eg. writes stories, letters
☐ Can write short notes, eg. shopping lists
☐ Can write own name and address without help
☐ Writes full name without help
☐ Writes name and address from copy
☐ Unable to write

**15. Time (Tick ONE only)**

☐ Regularly uses watch or clock to check timing of activities, eg. when a friend might call
☐ Tells time in hours and minutes, with clock or watch
☐ Knows what hour it is by the clock
☐ Shows by behaviour that he/she can anticipate some events of the day, eg. start of a television program

**16. Money (Tick ONE only)**

☐ Able to use money responsibly - no difficulty in coping with everyday money transactions; giving right amount and checking change
☐ Can select the amount of money appropriate to stated price of article
☐ Estimates roughly what different amounts might buy, eg. if given 50 cents has some idea of what he/she could get for that
☐ Picks out coins by name, eg. 50 cents, 10 cents
☐ No understanding of money

*Index of Social Competence 1982 R. McConkey & J. Walsh. Used with permission*

**17. Telephone (Tick ONE only)**

☐ Your son/daughter successfully answers and makes phone calls to/from both familiar and unfamiliar people almost all of the time

☐ Your son/ daughter answers phone calls successfully almost all of the time, and can make phone calls to both familiar and unfamiliar people if s/he prepares what s/he is going to say first (eg. by writing it down)

☐ Your son/daughter successfully answers and makes phone calls most of the time, but sometimes requires prompting or assistance particularly to/from unfamiliar people OR successfully answers and makes phone calls to relatives and friends without supervision but will not make calls to unfamiliar people

☐ Your son/daughter successfully answers and makes phone calls to relatives and/or friends about 25-90% of the time

☐ Your son/daughter successfully answers and makes phone calls to relatives and/or friends less than 25% of the time

☐ Your son/daughter will not use the phone at all

**18. Social Events (Tick ONE only)**

☐ Your son/daughter deals with a range of social events independently

☐ Your son/daughter deals with a range of social events independently, but you are concerned for his/her safety

☐ Your son/daughter deals with a range of social events independently, but s/he requires supervision on some occasions, particularly when attending an unfamiliar event or planning an event

☐ Your son/daughter deals with about 50-90% of his/her social events; for the remainder s/he requires help or supervision

☐ Your son/daughter deals with less than 25% of his/her social events; for the remainder s/he requires help or supervision

**19. New Skills (Tick ONE only)**

☐ Your son/daughter is able to learn a new skill or routine very quickly without extra help

☐ Your son/daughter is able to learn a new skill or routine without extra help, but may take longer than others

☐ Your son/daughter is able to learn a new skill or routine most of the time, but needs extra help or supervision if the task is fairly difficult

☐ Your son/daughter can learn a new skill or routine about 25-90% of the time; the rest of time s/he needs extra help or supervision or cannot learn it at all

☐ Your son/daughter can learn a new skill or routine less than 25% of the time; the rest of time s/he needs extra help or supervision or cannot learn it at

**20. Public Transport (Tick ONE only)**

☐ Your son/daughter is able to use public transport independently on both familiar and unfamiliar routes

☐ Your son/daughter is able to use public transport independently on both familiar and unfamiliar routes but you are concerned for his/her safety

☐ Your son/daughter is able to use public transport independently on familiar route(s), but requires supervision on unfamiliar routes

☐ Your son/daughter is able to use public transport on familiar routes about 25-90% of the time; the rest of time s/he needs supervision

☐ Your son/daughter is able to use public transport on familiar routes less than 25% of the time

☐ Your son/daughter always requires supervision when using public transport OR your son/daughter refuses to use public transport OR you do not allow your son/daughter to use public transport

# SECTION 6: DAILY OCCUPATIONS AND ACTIVITIES

This section asks about what your son / daughter is doing each day

**1. What year did your son/daughter leave school?**

☐ Still at school Year left school ___________

**2. Which statement best describes your son's /daughter's typical weekday?**

(Please tick all applicable and number of hours)

☐ Not working, but remaining home all day

☐ Taking part in activities funded by Alternatives to Employment (provides support for people who are unable to maintain full-time paid employment) eg. leisure activities, volunteer work.

Hours per week___________

☐ In a sheltered workshop/business services environment. Hours per week___________

☐ Attending post secondary school classes in a TAFE-like college environment

Hours per week___________

☐ In an open work environment. Hours per week___________

☐ Other (please specify)____________________________________________________

**3. Ideally how would you like to see your son/daughter spend their day?**

(Please tick all applicable and number of hours)

☐ Not working, but remaining home all day

☐ Taking part in activities funded by Alternatives to Employment (provides support for people who are unable to maintain full-time paid employment) eg. leisure activities, volunteer work.

Hours per week___________

☐ In a sheltered workshop/business services environment. Hours per week___________

☐ Attending post secondary school classes in a TAFE-like college environment

Hours per week___________

☐ In an open work environment. Hours per week___________

☐ Other (please specify) ______________________________________________

**4. If the ideal does not match reality can you tell us why?**

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

5. **Is your son/daughter taking part in Post School Options and receiving Alternatives to Employment funding?**

☐ No, please go to question 6.
☐ Yes, please provide details of their activities within the last 12 months

| Service Provider | Activities | Hours per week |
|---|---|---|
| eg. Activ/Rocky Bay/Intework | eg. support in workplace/leisure activities/ recreation activities | eg. 8 hours |
| | | |
| | | |
| | | |
| | | |

6. **Is your son/daughter taking part in paid employment?**

☐ No, go to question 8.
☐ Yes, please provide details of employment within the last 12 months.

| Job Title | Hours per week | Period of employment | Hourly rate | Support received in workplace |
|---|---|---|---|---|
| eg. Shop assistant | eg. 20 hours | eg. Jan 2010 - present | eg. $6.50 per hour | ☐ Formal supports (support worker)<br>☐ Natural supports (colleagues/supervisor)<br>☑ No supports |
| | | | | ☐ Formal supports (support worker)<br>☐ Natural supports (colleagues/supervisor)<br>☐ No supports |
| | | | | ☐ Formal supports (support worker)<br>☐ Natural supports (colleagues/supervisor)<br>☐ No supports |

7. **Please rate your son's /daughter's level of satisfaction in this job (circle a number)**

| Not at all satisfied | | | | | | | Extremely satisfied |
|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

**8. Please indicate the main reason(s) why your son/daughter is not currently employed (tick all that apply).**

☐ Not ready for work
☐ Has high support needs
☐ Not willing to work
☐ Has difficult/challenging behaviours
☐ Poor physical health
☐ Transport difficulties
☐ Insufficient services
☐ Inadequate services
☐ Funding not available
☐ Problems at previous workplace
☐ No appropriate job vacancies

**9. Does your son/daughter take part in any other sport or social activities on a regular basis which you have not yet listed?**

| Activity | Organisation | Hours per week |
|---|---|---|
| eg. Swimming club/social group/dancing | eg. Belmont Oasis Leisure Centre/Down Syndrome Association/Dancing for the Disabled | eg. 4 hours per week /2 hours per week |
| | | |
| | | |
| | | |
| | | |

**10. With whom does your son/daughter participate in these activities? (Please tick all that apply)**

☐ Similar aged peers without disabilities
☐ Paid employee (support person, recreational aide)
☐ Peers with disabilities
☐ Sibling with/without sibling's friends
☐ Friend of the family/neighbour/church member
☐ Other relatives
☐ Parents
☐ Other ______________________________

**11. Do you feel your son's/daughter's needs are being met under the current day activity arrangements?**

☐ Yes
☐ No, please describe why you think they are not being met and how they could be met.

_______________________________________________

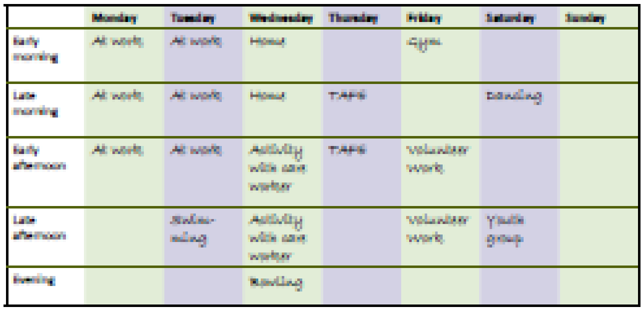
_______________________________________________

**Please fill in the weekly diary below with activities that your son/daughter would participate in, during a typical week.**

Include details of:

- Employment (open, sheltered, volunteer work)
- Education (TAFE, college, school)
- Leisure activities (sport, drama, arts, etc.)

## COMPLETED EXAMPLE



| | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday | Sunday |
|---|---|---|---|---|---|---|---|
| Early morning | At work | At work | Home | | Gym | | |
| Late morning | At work | At work | Home | TAFE | | Dancing | |
| Early afternoon | At work | At work | Activity with care worker | TAFE | Volunteer work | | |
| Late afternoon | | Swimming | Activity with care worker | | Volunteer work | Youth group | |
| Evening | | | Bowling | | | | |

| | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday | Sunday |
|---|---|---|---|---|---|---|---|
| Early morning | | | | | | | |
| Late morning | | | | | | | |
| Early afternoon | | | | | | | |
| Late afternoon | | | | | | | |
| Evening | | | | | | | |

# SECTION 7: YOUNG ADULT'S QUALITY OF LIFE

### KIDSCREEN

How is your son/daughter? How does he/she feel? This is what we would like to know from you.

Please answer the following questions to the best of your knowledge, ensuring that the answers you give reflect the perspective of your son/daughter. Please try to remember your son's /daughter's experiences over a typical week.

**PHYSICAL ACTIVITIES AND HEALTH**

**Thinking about a typical week….**

| | | | | | | |
|---|---|---|---|---|---|---|
| 1. | In general, how would you rate your son's/daughter's health? | ☐<br>excellent | ☐<br>very good | ☐<br>good | ☐<br>fair | ☐<br>poor |
| 2. | Has your son/daughter felt fit and well? | ☐<br>not at all | ☐<br>slightly | ☐<br>moderately | ☐<br>very | ☐<br>extremely |
| 3. | Has your son/daughter been physically active (eg. running, swimming, biking)? | ☐<br>not at all | ☐<br>slightly | ☐<br>moderately | ☐<br>very | ☐<br>extremely |
| 4. | Has your son/daughter been able to run well? | ☐<br>not at all | ☐<br>slightly | ☐<br>moderately | ☐<br>very | ☐<br>extremely |
| 5. | Has your son/daughter felt full of energy? | ☐<br>never | ☐<br>seldom | ☐<br>quite often | ☐<br>very often | ☐<br>always |

**GENERAL MOOD AND YOUR SON'S/DAUGHTER'S FEELINGS**

**Thinking about a typical week….**

| | | | | | | |
|---|---|---|---|---|---|---|
| 6. | Has your son/daughter felt that life was enjoyable? | ☐<br>not at all | ☐<br>slightly | ☐<br>moderately | ☐<br>very | ☐<br>extremely |
| 7. | Has your son/daughter been in a good mood? | ☐<br>never | ☐<br>seldom | ☐<br>quite often | ☐<br>very often | ☐<br>always |
| 8. | Has your son/daughter had fun? | ☐<br>never | ☐<br>seldom | ☐<br>quite often | ☐<br>very often | ☐<br>always |
| 9. | Has your son/daughter felt sad? | ☐<br>never | ☐<br>seldom | ☐<br>quite often | ☐<br>very often | ☐<br>always |
| 10. | Has your son/daughter felt so bad that they didn't want to do anything? | ☐<br>never | ☐<br>seldom | ☐<br>quite often | ☐<br>very often | ☐<br>always |
| 11. | Has your son/daughter felt lonely? | ☐<br>never | ☐<br>seldom | ☐<br>quite often | ☐<br>very often | ☐<br>always |
| 12. | Has your son/daughter been happy with the way they are? | ☐<br>never | ☐<br>seldom | ☐<br>quite often | ☐<br>very often | ☐<br>always |

**FAMILY AND YOUR SON'S/DAUGHTER'S FREE TIME**

**Thinking about a typical week….**

| | | | | | |
|---|---|---|---|---|---|
| 13. Has your son/daughter had enough time for themselves? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 14. Has your son/daughter been able to do the things that they want to do in their free time? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 15. Has your son/daughter felt that their parent(s) had enough time for them? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 16. Has your son/daughter felt that their parent(s) treated them fairly? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 17. Has your son/daughter been able to talk to their parent(s) when they wanted to? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 18. Has your son/daughter had enough money to do the same things as their friends? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 19. Has your son/daughter felt that they had enough money for their expenses? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |

**FRIENDS**

**Thinking about a typical week….**

| | | | | | |
|---|---|---|---|---|---|
| 20. Has your son/daughter spent time with their friends? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 21. Has your son/daughter had fun with their friends? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 22. Have your son/daughter and their friends helped each other? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 23. Has your son/daughter been able to rely on their friends? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |

**DAILY ACTIVITIES**

**Thinking about a typical week….**

| | | | | | |
|---|---|---|---|---|---|
| 24. Has your son/daughter been happy in their daily activities? | ☐ not at all | ☐ slightly | ☐ moderately | ☐ very | ☐ extremely |
| 25. Has your son/daughter got on well at their daily activities? | ☐ not at all | ☐ slightly | ☐ moderately | ☐ very | ☐ extremely |
| 26. Has your son/daughter been able to pay attention? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |
| 27. Has your son/daughter got along well with his/her supervisors? | ☐ never | ☐ seldom | ☐ quite often | ☐ very often | ☐ always |

# SECTION 8: RESOURCES AND INCOME

**1. If you or your spouse are receiving any benefits or pensions due to your son's / daughter's disability, or if your son/daughter is receiving any benefits or pensions, please tick the corresponding box below.**

☐ Disability support pension
☐ Special benefit
☐ Mobility allowance
☐ Education allowance (Pensioner education supplement)
☐ Carer allowance
☐ Youth Disability Supplement
☐ Youth Allowance
☐ Unemployment allowance
☐ Sickness allowance
☐ Carer payment (means tested)
☐ Other: ______________________________

**2. Which words best describe your family's money situation? (Please only tick one box)**

☐ We are spending money we haven't got
☐ We have just enough money to get us through to the next pay day
☐ There's some money left over each week but we just spend it
☐ We save a bit every now and then
☐ We can save a lot

**3. What do you estimate the combined gross parental income (before tax) was in the 2010/2011 financial year, not including benefits and pensions? (Please only tick one box)**

☐ Less than $18,199
☐ Between $18,200 and $33,799
☐ Between $33,800 and $41,599
☐ Between $41,600 and $51,999
☐ Between $52,000 and $72,799
☐ Between $72,800 and $88,399
☐ Between $88,400 and $129,999
☐ $130,000 and above

**4. How available is transport by car (own car or provided by others)?**

| Not at all adequate | Seldom adequate | Sometimes adequate | Usually adequate | Almost always adequate | Not applicable |
|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**5. How accessible is public transport?**

| Not at all adequate | Seldom adequate | Sometimes adequate | Usually adequate | Almost always adequate | Not applicable |
|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**6. Does your son/daughter with Down syndrome use public transport?**

☐ Yes ☐ No

# SECTION 9: ENVIRONMENTAL INFLUENCES

This section asks about environmental influences on your son's/ daughter's daily activities and what helps and what hinders what they are doing.

To answer these questions we would like you to consider whether something is a minor/medium/major barrier (ie. hinders the task) OR a minor/medium/major facilitator (ie. helps achieve the task) or has No influence.
For example, in the first question "How do social networks influence your son's/ daughter's accomplishment of his/ her daily activities?"
Applying this to: "3. Support from their friends" your answer may be minor facilitator (tick Minor facilitator +1), indicating that their friends provide some help in their achievement of daily activities.

| | | Influence Scale | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Barrier ←→ Facilitators | | | | | | | I do not know | Does not apply |
| | | Major | Medium | Minor | No influence | Minor | Medium | Major | | |
| **How do social networks influence your son's /daughter's accomplishment of his/her daily activities?** | | | | | | | | | | |
| 1. | Their family situation (living alone, with a spouse, or with children) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 2. | Support from members of their family or close friends who take the place of family (presence, physical assistance, household assistance, encouragement) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 3. | Support from their friends | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 4. | Support from their neighbours | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 5. | Support from their colleagues at work, school or place of principal occupation | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| **How do attitudes of the people around your son/daughter influence their accomplishment of daily activities?** | | | | | | | | | | |
| 6. | Attitudes of their family or close friends who take the place of family towards your son/daughter | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 7. | Attitudes of their friends towards your son/ daughter | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 8. | Attitudes of their colleagues at work, school or place of principal occupation towards your son/ daughter | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 9. | Attitudes of their superiors (supervisors, employers) towards your son/daughter | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 10. | Attitudes of their neighbours towards your son/ daughter | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 11. | Attitudes of those providing services in the community (shop assistants, government employees, etc.) towards your son/daughter | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |

| | | Influence Scale | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Barrier ←→ Facilitators | | | | | | | I do not know | Does not apply |
| | | Major | Medium | Minor | No influence | Minor | Medium | Major | | |
| 12. | Attitudes of strangers towards your son/daughter (people that he/she pass on the street) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 13. | Attitudes of people towards your son/daughter when they are in a group (a class, a crowd, social group, etc.) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 14. | The religious beliefs of the people in your community | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| **How do employment services influence your son's/daughter's accomplishment of daily activities?** | | | | | | | | | | |
| 15. | Counselling and employment seeking services | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 16. | Current availability of jobs in your community | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 17. | Job criteria and selection tests | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| *If they are not currently employed, tick here and go to the next section.* | | | | | ☐ | | | | | |
| 18. | Their workplace (physical set-up of your place of work) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 19. | The requirements of their work tasks (expectations, performance, qualities needed, etc.) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 20. | Their work hours | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 21. | Union structures | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 22. | Employee services | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| **How do financial resources and benefits influence your son's/daughter's accomplishment of daily activities?** | | | | | | | | | | |
| 23. | Their personal income (or your families' if they do not have their own income) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 24. | Public disability programs (eg. disability support pension) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 25. | Private health insurance programs (eg. Hospital benefits) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| **How do commercial services influence your son's/daughter's accomplishment of daily activities?** | | | | | | | | | | |
| 26. | The availability of businesses in their community (grocery store, restaurants, hardware store, department stores, shopping centres, etc.) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 27. | The services offered by the businesses in their community | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| **How do other support services influence your son's/daughter's accomplishment of daily activities?** | | | | | | | | | | |
| 28. | Support workers other than those provided by their family and close friends | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 29. | Home care services other than those provided by their family and close friends | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |

| | | Influence Scale | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Barrier ←→ Facilitators | | | | | | | | |
| | | Major | Medium | Minor | No influence | Minor | Medium | Major | I do not know | Does not apply |
| 30. | Health services in their community (hospital, medical clinic, dentist, etc.) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 31. | Physical and social rehabilitation services in their community | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 32. | Vocational services within their community | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 33. | Social integration support services (social work, residential resources, etc.) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| **How do educational services influence your son's/daughter's accomplishment of daily activities?** | | | | | | | | | | |
| *If they are not currently studying, tick here and go to the next section.* ☐ | | | | | | | | | | |
| 34. | Educational services in their community (eg. TAFE, college, skills training) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 35. | Access to student loans and scholarships | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 36. | Other educational services in their community (extra-curricular) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| **How do public infrastructure services influence your son's/daughter's accomplishment of daily activities?** | | | | | | | | | | |
| 37. | Public transport services in their community (schedule, stops, frequency, routes, etc.) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 38. | Specially routed buses/ trains to meet the needs of young people with disabilities | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 39. | Long distance transport services (train, bus, plane) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 40. | Communication services in their environment (telephone, fax, internet) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 41. | Radio media services | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 42. | Television media services | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| **How do community organisation services influence your son's/daughter's accomplishment of daily activities?** | | | | | | | | | | |
| 43. | Cultural services in their community (cinema, theatre, library, etc.) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 44. | Religious organisation services in their community | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 45. | Athletic and recreational organisation services in their community (sports, bowling, travel, outdoor recreation, gym) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |
| 46. | Community organisation services in their community (self-help groups, craft/social groups) | -3 | -2 | -1 | 0 | +1 | +2 | +3 | ☐ | ☐ |

| Comments |
|---|
| |

# SECTION 10: ACCOMMODATION

**1. Please indicate your son's/daughter's usual place of residence.**

☐ Family home (ie. With parents)
☐ Group home type accommodation
☐ Hostel
☐ Hospital or nursing home
☐ Unit or house, living with relatives and/or friends
☐ Unit or house, living alone
☐ Other: ____________________________________

**2. If your son/daughter lives at home, what are your plans or expectations about your son/daughter moving into out-of-family-home accommodation in the future?**

☐ Out-of-family-home accommodation will definitely not be wanted or needed for our son/daughter.
☐ We may consider out-of-family-home accommodation in the future, but only under extreme circumstances.
☐ We may consider out-of-family-home accommodation for our son/daughter, but not for the next 20 years or so.
☐ We may consider out-of-family-home accommodation for our son/daughter in the next 10 years.
☐ We may consider out-of-family-home accommodation for our son/daughter in the next 5 years.
☐ We have been looking at accommodation options for our son/daughter out of interest at this stage.
☐ We have been looking at accommodation options for our son/daughter seriously.
☐ We have applied for accommodation funding, and are awaiting the outcome.
☐ We applied for accommodation funding, but we were unsuccessful.
☐ We have received accommodation funding and are in the process of organising accommodation options for our son/daughter.

**3. Please comment in the space below about why you will or will not consider out-of-family-home accommodation for your son/daughter, and any concerns you may have about it. If you applied for funds but were unsuccessful, please also comment on the reasons given:**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

# SECTION 11: SOCIAL RELATIONSHIPS

Friendships and participation in social/leisure activities are important for young people and may change over time.

**1. Does your son's/daughter's social network contain:**

☐ No friends
☐ 1 or 2 close friends
☐ Between 3 to 6 close friends
☐ More than 6 close friends

**2. Does you son's/daughter's social network contain more friends with or without disabilities?**

☐ With disabilities
☐ Without disabilities
☐ Not applicable

**3. How frequently does your son/daughter have the opportunity to interact in social activites with peers without disabilities?**

| Never | Rarely | Sometimes | Frequently | Almost always |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**4. How frequently does your son/daughter have the opportunity to interact in social activities with peers with disabilities?**

| Never | Rarely | Sometimes | Frequently | Almost always |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**5. How frequently does your son/daughter have the opportunity to interact in social activities with family members and relatives?**

| Never | Rarely | Sometimes | Frequently | Almost always |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

# SECTION 12: RESPITE

Respite care is a short term, temporary break for those people who are caring for family members who need support in their daily functioning; it is designed to back up and maintain the primary care giving relationship.

In thinking about the above definition of respite please answer the following questions.

1. Have you received any IN-HOME respite care for your son/daughter in the LAST 12 MONTHS?

☐ No
☐ Yes - How many times?____________
- How many hours do you usually receive?____________

2. Has your son/daughter been in OVERNIGHT respite care outside the home in the LAST 12 MONTHS?

☐ No
☐ Yes - How many nights?____________

3. Please feel free to make any comments about respite support

________________________________________

________________________________________

________________________________________

4. Have you as carer organised or taken irregular or regular short-term, temporary breaks other than those listed above in the LAST 12 MONTHS (eg. respite camps for parents, holiday)?

☐ No
☐ Yes - How many nights?____________

5. Please feel free to make any comments about experiencing this form of respite support

________________________________________

________________________________________

________________________________________

# SECTION 13: PARTICIPATION

## LIFE- H

**This section is designed to gather information on a group of life habits that your son/daughter accomplishes in their environments (home, work, school and neighbourhood). There are 12 domains, each one reflecting a different area of life. For example, nutrition, fitness, personal care, communication etc. Within each life domain there are a number of more specific questions. Each question requires three answers; Level of Accomplishment, Type of Assistance and Level of Satisfaction.**

**Level of Accomplishment (Can they do the task)**
This question refers to how well the life habit is completed. Please tick one level of accomplishment. The following descriptions explain how each level of accomplishment is defined.

**No difficulty**
Your son/daughter completes this life habit with little or no difficulty, even if it requires an adaptation (eg. modified environment), assistive device (equipment) or human assistance (physical assistance or verbal cues).

**With difficulty**
Your son/daughter completes this life habit with difficulty (discomfort, a lot of effort etc.).

**Accomplished by other person**
This life habit is entirely accomplished by another person (washing, dressing, moving around etc.)

**Not accomplished**
Your son/daughter cannot accomplish this life habit because:
a) the disabilities are too severe,
b) the obstacles are too great, or
c) there is a lack of assistance

**Not applicable**
This activity is not part of your son's /daughter's daily activities because of:
a) never having done it or needed to do it
b) age or gender
c) the person's environment
d) a personal, social or socio-cultural choice

**Type of Assistance (What help do they need)**
This question asks about assistance required to complete the task. Please tick at least one box (you may tick more than one). Here are the definitions of each type of assistance.

**No assistance**
Your son/daughter accomplishes the life habit independently.

**Assistive device**
Any non-human device used to assist in the accomplishment of life habits. For example, a visual aid, a hearing aid or other adapted equipment.

**Adaptation**
Any modification to the person's environment or task to facilitate the accomplishment of the life habit. For example, an access ramp, lighting modifications, adaptation of the task, modification of the life habit or modification of the amount of time required to accomplish it.

**Human assistance**
This is defined as any person who assists in the accomplishment of the life habit, including family, friends, medical personnel etc. This includes physical assistance or supervision, verbal cues, encouragement.

**Level of Satisfaction**
The question relates to how satisfied you think your son/daughter is with the way they accomplish that life habit. The "more or less satisfied" level of satisfaction means that in certain situations or on certain days your son/daughter is satisfied and on other days you think your son/daughter is dissatisfied with the level of accomplishment. Each life habit's level is only an indicator; mainly, to decide the relevance of an intervention on the modification of a life habit.

## Answer the following questions.

**(Check the appropriate boxes.)**

1. For each of the following life habits, indicate
A. How the person generally accomplishes it, and
B. The type of assistance required to accomplish it
2. For each of the following life habits, indicate the level of satisfaction with the way it is accomplished.

Note: Keep in mind that answers should reflect the person's usual way of carrying out life habits.

| | Question 1 | | | | | | | | | Question 2 | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A. Level of Accomplishment (Check only 1) | | | | | B. Type of Assistance (Check 1 or more as required) | | | | Level of Satisfaction (Check only 1) | | | | |
| | No difficulty | With difficulty | Accomplished by other person | Not accomplished | Not applicable | No assistance | Assistive device | Adaptation | Human assistance | Very dissatisfied | Dissatisfied | More or less satisfied | Satisfied | Very satisfied |
| **1. NUTRITION** | | | | | | | | | | | | | | |
| Selecting appropriate food for meals, according to taste and particular needs (quantity, type of food) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Preparing meals (including using electric kitchen appliances) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Eating meals (including the use of dishes, utensils and standard table manners) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Eating in restaurants (table service and fast-food) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **2. FITNESS** | | | | | | | | | | | | | | |
| Getting in and out of bed | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Sleep (comfort, duration, continuity, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Participating in physical activities to maintain or improve physical fitness or health (walking, individual or group exercise) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Participating in relaxation, unwinding, or mental focus activities to ensure psychological or mental wellbeing (yoga, meditation, personal growth, chess, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **3. PERSONAL CARE** | | | | | | | | | | | | | | |
| Attending to personal hygiene (washing, doing hair, taking a bath or shower, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using the bathroom and toilet in the home | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using a bathroom and toilet other than those in the home | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Dressing and undressing the upper half of their body (clothing, accessories, including the choice of appropriate clothes) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Dressing and undressing the lower half of their body (clothing, accessories, including the choice of appropriate clothes) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Putting on, removing, and maintaining assistive devices (orthotics, prosthetics, contact lenses, glasses, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Taking care of their health (first aid, medication, following treatment instructions, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using services provided by a medical clinic, hospital or rehabilitation centre | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Answer the following questions.
**(Check the appropriate boxes.)**

**1.** For each of the following life habits, indicate
A. How the person generally accomplishes it, and
B. The type of assistance required to accomplish it

**2.** For each of the following life habits, indicate the level of satisfaction with the way it is accomplished.

Note: Keep in mind that answers should reflect the person's usual way of carrying out life habits.

| | Question 1 | | | | | | | | | Question 2 | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A. Level of Accomplishment (Check only 1) | | | | | B. Type of Assistance (Check 1 or more as required) | | | | Level of Satisfaction (Check only 1) | | | | |
| | No difficulty | With difficulty | Accomplished by other person | Not accomplished | Not applicable | No assistance | Assistive device | Adaptation | Human assistance | Very dissatisfied | Dissatisfied | More or less satisfied | Satisfied | Very satisfied |
| **4. COMMUNICATION** | | | | | | | | | | | | | | |
| Communicating with another person at home or in the community (expressing needs, holding a conversation, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Communicating with a group of people at home or in the community (expressing needs, holding a conversation, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Written communication (writing message, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Reading and understanding written information (newspapers, books)<br>Note: If they use glasses to read, tick Assistive device | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using a phone at home or at work | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using a mobile phone | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using a computer | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using a radio, television or sound system | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **5. HOUSING** | | | | | | | | | | | | | | |
| Taking part in housekeeping tasks (light cleaning, making bed, tidying up, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Taking part in maintaining the grounds (lawncare) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Entering and exiting the home | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Moving around within the home | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using the furniture and equipment at home (table, storage space, lighting, outdoor play equipment, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Moving around outside the home (backyard, grounds) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **6. MOBILITY** | | | | | | | | | | | | | | |
| Getting around on streets or sidewalks (including crossing streets) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Getting around on slippery or uneven surfaces (grass, gravel, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Driving a vehicle | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Answer the following questions.
**(Check the appropriate boxes.)**

1. For each of the following life habits, indicate
   A. How the person generally accomplishes it, and
   B. The type of assistance required to accomplish it
2. For each of the following life habits, indicate the level of satisfaction with the way it is accomplished.

Note: Keep in mind that answers should reflect the person's usual way of carrying out life habits.

| | Question 1 | | | | | | | | | Question 2 | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **A. Level of Accomplishment** (Check only 1) | | | | | **B. Type of Assistance** (Check 1 or more as required) | | | | **Level of Satisfaction** (Check only 1) | | | | |
| | No difficulty | With difficulty | Accomplished by other person | Not accomplished | Not applicable | No assistance | Assistive device | Adaptation | Human assistance | Very dissatisfied | Dissatisfied | More or less satisfied | Satisfied | Very satisfied |
| Riding a bicycle (for transportation, recreations, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Being a passenger in a vehicle (car, bus, taxi, etc.)<br>Note: Adapted transport is an adaptation. | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **7. RESPONSIBILITIES** | | | | | | | | | | | | | | |
| Recognising the value of money and correctly using the different denominations of paper and coin money | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using bank cards and automatic teller machines (ATMs) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Making purchases (choosing merchandise, mode or payment) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Planning a budget and meeting financial obligations (spending, saving, paying bills, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Assuming responsibilities towards others and society (respecting the rights and property of others, voting, obeying laws and by-laws, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Assuming personal or familial responsibilities | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **8. INTERPERSONAL RELATIONSHIPS** | | | | | | | | | | | | | | |
| Maintaining a close relationship with their partner | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Maintains close relationships with their parents | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Maintaining close relationships with other members of the family (brothers, sisters, uncles, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Maintaining friendships | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Maintaining social relationships with those around them (neighbours, co-workers, fellow students, leisure activities, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Having a sexual relationship (healthy, appropriate, safe sex) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **9. COMMUNITY LIFE** | | | | | | | | | | | | | | |
| Getting to public buildings in the community (governmental, banks, library, postal, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Entering and getting around in public buildings in the community (governmental, banks, library, postal, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using the public services in the community (governmental, banks, library, postal, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Answer the following questions.
**(Check the appropriate boxes.)**

1. For each of the following life habits, indicate
   A. How the person generally accomplishes it, and
   B. The type of assistance required to accomplish it
2. For each of the following life habits, indicate the level of satisfaction with the way it is accomplished.

Note: Keep in mind that answers should reflect the person's usual way of carrying out life habits.

| | **Question 1** | | | | | | | | | **Question 2** | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **A. Level of Accomplishment** (Check only 1) | | | | | **B. Type of Assistance** (Check 1 or more as required) | | | | **Level of Satisfaction** (Check only 1) | | | | |
| | No difficulty | With difficulty | Accomplished by other person | Not accomplished | Not applicable | No assistance | Assistive device | Adaptation | Human assistance | Very dissatisfied | Dissatisfied | More or less satisfied | Satisfied | Very satisfied |
| Getting to commercial establishments in the community (supermarket, shopping centre, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Entering and moving around in commercial establishments in the community (supermarket, shopping centre, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using neighbourhood businesses (supermarket, shopping centre, dry cleaners, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Participating in social or community groups (social clubs, charity or religious groups, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Participating in spiritual or religious practices | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **10. EDUCATION** | | | | | | | | | | | | | | |
| Participating in educational activities or vocational training at the high school level (courses, homework, extracurricular activities, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Undertaking vocational training (TAFE, university, community college, work experience) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **11. SEEKING EMPLOYMENT** | | | | | | | | | | | | | | |
| *If they are not seeking employment, tick here and go to the next section.* ☐ | | | | | | | | | | | | | | |
| Choosing a trade or profession | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Seeking a regular job (preparing a resumé, contacting an employer, interview, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Seeking temporary employment (seasonal, student employment, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using placement and guidance services (other than those in the school environment) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **Paid Employment** | | | | | | | | | | | | | | |
| Holding a paid job (If they are not currently working, tick "Not accomplished") | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Interacting with colleagues | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using the infrastructures of their place of employment (cafeterias, staff room, personnel services, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

## Answer the following questions.

**(Check the appropriate boxes.)**

1. For each of the following life habits, indicate A. How the person generally accomplishes it, and B. The type of assistance required to accomplish it
2. For each of the following life habits, indicate the level of satisfaction with the way it is accomplished.

Note: Keep in mind that answers should reflect the person's usual way of carrying out life habits.

| | Question 1 | | | | | | | | | Question 2 | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A. Level of Accomplishment (Check only 1) | | | | | B. Type of Assistance (Check 1 or more as required) | | | | Level of Satisfaction (Check only 1) | | | | |
| | No difficulty | With difficulty | Accomplished by other person | Not accomplished | Not applicable | No assistance | Assistive device | Adaptation | Human assistance | Very dissatisfied | Dissatisfied | More or less satisfied | Satisfied | Very satisfied |
| **Volunteer Employment** | | | | | | | | | | | | | | |
| Doing volunteer work as their main occupation | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Carrying out family or domestic tasks as their main occupation | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Carrying out volunteer activities as a secondary occupation | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Attending a day-centre as a principal occupation | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Getting to, entering, and moving around within their place of occupation, paid or not (work, study, volunteer, day-centre, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| **12. RECREATION** | | | | | | | | | | | | | | |
| Participating in sporting or recreational activities (walking, sports, games, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Participating in artistic, cultural or craft activities (music, dance, woodworking, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Going to sporting events (hockey, football) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Going to artistic or cultural events (concerts, movies, theatre, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Participating in tourist activities (travelling, visiting natural or historic sites, camping, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Taking part in outdoor activities (bush walking, camping, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Using neighbourhood recreational services (library, municipal recreation centre, etc.) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

**Please feel free to provide any comments:**

# SECTION 14: PERSONALITY AND BEHAVIOUR

**Many of the following behaviours may not apply to your son/daughter. For each item that does describe your son/daughter, now or within the PAST SIX MONTHS, please tick the circle for 2 if the item is very true or often true. Tick the circle for 1 if the item is somewhat or sometimes true of your son/daughter. If the item is not true of your child, tick the circle for 0.**

**If your son/daughter is unable to perform an item, tick the circle for 0. For example, if your son/daughter has no speech, then for the item "Talks too much or too fast" tick the circle for 0.**

| | Not true as far as you know 0 | Somewhat or sometimes true 1 | Very true or often true 2 |
|---|---|---|---|
| 1. Appears depressed, downcast or unhappy | ○ | ○ | ○ |
| 2. Avoids eye contact. Won't look you straight in the eye | ○ | ○ | ○ |
| 3. Aloof, in his/her own world | ○ | ○ | ○ |
| 4. Abusive. Swears at others | ○ | ○ | ○ |
| 5. Arranges objects or routine in a strict order | ○ | ○ | ○ |
| Please describe: | | | |
| 6. Bangs head | ○ | ○ | ○ |
| 7. Becomes over-excited | ○ | ○ | ○ |
| 8. Bites others | ○ | ○ | ○ |
| 9. Bizarre speech | ○ | ○ | ○ |
| Please describe: | | | |
| 10. Cannot attend to one activity for any length of time, poor attention span | ○ | ○ | ○ |
| 11. Chews or mouths objects, or body parts | ○ | ○ | ○ |
| 12. Cries easily for no reason, or over small upsets | ○ | ○ | ○ |
| 13. Covers ears or is distressed when hears particular sounds | ○ | ○ | ○ |
| Please describe: | | | |
| 14. Confuses the use of pronouns, eg. uses "you" instead of "I" | ○ | ○ | ○ |
| 15. Deliberately runs away | ○ | ○ | ○ |
| 16. Delusions: has a firmly held belief or idea that can't possibly be true | ○ | ○ | ○ |
| Please describe: | | | |
| 17. Distressed about being alone | ○ | ○ | ○ |
| 18. Doesn't show affection | ○ | ○ | ○ |
| 19. Doesn't respond to others' feelings, eg. shows no response if a family member is crying | ○ | ○ | ○ |

|  | Not true as far as you know 0 | Somewhat or sometimes true 1 | Very true or often true 2 |
|---|---|---|---|
| 20. Easily distracted from his/her task, eg. by noises | ○ | ○ | ○ |
| 21. Easily led into trouble by others | ○ | ○ | ○ |
| 22. Eats non-food items, eg. dirt, grass, soap | ○ | ○ | ○ |
| 23. Excessively distressed if separated from familiar person | ○ | ○ | ○ |
| 24. Fears particular things or situations, eg. the dark or insects | ○ | ○ | ○ |
| Please describe: |  |  |  |
| 25. Facial twitches or grimaces | ○ | ○ | ○ |
| 26. Flicks, taps, twirls objects repeatedly | ○ | ○ | ○ |
| 27. Fussy eater or has food fads | ○ | ○ | ○ |
| 28. Gorges food. Will do anything to get food, eg. takes food out of bins or steals food | ○ | ○ | ○ |
| 29. Gets obsessed with an idea or activity | ○ | ○ | ○ |
| Please describe: |  |  |  |
| 30. Grinds teeth | ○ | ○ | ○ |
| 31. Has become confused or forgetful | ○ | ○ | ○ |
| 32. Has become more withdrawn | ○ | ○ | ○ |
| 33. Has nightmares, night terrors or walks in sleep | ○ | ○ | ○ |
| 34. Has temper tantrums, eg. stamps feet, slams doors | ○ | ○ | ○ |
| 35. Hides things | ○ | ○ | ○ |
| 36. Hits self or bites self | ○ | ○ | ○ |
| 37. Hums, whines, grunts, squeals, or makes other non-speech noises | ○ | ○ | ○ |
| 38. Impatient | ○ | ○ | ○ |
| 39. Inappropriate sexual activity with another | ○ | ○ | ○ |
| 40. Increase in appetite | ○ | ○ | ○ |
| 41. Impulsive, acts before thinking | ○ | ○ | ○ |
| 42. Irritable | ○ | ○ | ○ |
| 43. Jealous | ○ | ○ | ○ |
| 44. Kicks, hits or injures others | ○ | ○ | ○ |
| 45. Lacks self-confidence, poor self-esteem | ○ | ○ | ○ |
| 46. Laughs or giggles for no obvious reason | ○ | ○ | ○ |
| 47. Lights fires | ○ | ○ | ○ |
| 48. Likes to hold or play with an unusual object, eg. string, twigs; overly fascinated with something, eg. water | ○ | ○ | ○ |
| Please describe: |  |  |  |

|  | Not true as far as you know 0 | Somewhat or sometimes true 1 | Very true or often true 2 |
|---|---|---|---|
| 49. Loss of appetite | ○ | ○ | ○ |
| 50. Loss of enjoyment or interest in usual activities | ○ | ○ | ○ |
| 51. Loss of self-care skills | ○ | ○ | ○ |
| 52. Makes gloomy statements | ○ | ○ | ○ |
| 53. Masturbates or exposes self in public | ○ | ○ | ○ |
| 54. Mood changes rapidly for no apparent reason | ○ | ○ | ○ |
| 55. Moves slowly, underactive, does little, eg. only sits and watches others | ○ | ○ | ○ |
| 56. Noisy or boisterous | ○ | ○ | ○ |
| 57. Not communicating as much as usual | ○ | ○ | ○ |
| 58. Overactive, restless, unable to sit still | ○ | ○ | ○ |
| 59. Overaffectionate | ○ | ○ | ○ |
| 60. Overbreathes, vomits, has headaches or complains of being sick for no physical reason | ○ | ○ | ○ |
| 61. Overly attention-seeking | ○ | ○ | ○ |
| 62. Overly interested in looking at, listening to or dismantling mechanical things, eg. lawnmower, vacuum cleaner | ○ | ○ | ○ |
| 63. Panics. Sweats, flushes, trembles | ○ | ○ | ○ |
| 64. Poor sense of danger | ○ | ○ | ○ |
| 65. Prefers to do things on his/her own. Tends to be a loner | ○ | ○ | ○ |
| 66. Preoccupied with only one or two particular interests | ○ | ○ | ○ |
| Please describe: |  |  |  |
| 67. Problems with cigarettes, alcohol or caffeine | ○ | ○ | ○ |
| 68. Problems with the illegal use of drugs | ○ | ○ | ○ |
| 69. Refuses to go to college, activity centre or workplace | ○ | ○ | ○ |
| 70. Repeated movements of hands, body, head or feet, eg. handflapping or rocking | ○ | ○ | ○ |
| 71. Resists being cuddled, touched or held | ○ | ○ | ○ |
| 72. Repeats back what others say like an echo | ○ | ○ | ○ |
| 73. Repeats the same word or phrase over and over | ○ | ○ | ○ |
| 74. Smells, tastes, or licks objects | ○ | ○ | ○ |
| 75. Scratches or picks his/her skin | ○ | ○ | ○ |
| 76. Screams a lot | ○ | ○ | ○ |
| 77. Sleeps too little. Disrupted sleep. | ○ | ○ | ○ |
| 78. Stares at lights or spinning objects | ○ | ○ | ○ |
| 79. Sleeps too much or overly drowsy | ○ | ○ | ○ |

|  | Not true as far as you know 0 | Somewhat or sometimes true 1 | Very true or often true 2 |
|---|---|---|---|
| 80. Soils outside toilet though toilet trained. Smears or plays with faeces | ○ | ○ | ○ |
| 81. Speaks in whispers, high pitched voice, or other unusual tone or rhythm | ○ | ○ | ○ |
| 82. Spits | ○ | ○ | ○ |
| 83. Switches lights on and off, pours water over and over; or similar repetitive activity | ○ | ○ | ○ |
| Please describe: |  |  |  |
| 84. Steals | ○ | ○ | ○ |
| 85. Stubborn, disobedient or uncooperative | ○ | ○ | ○ |
| 86. Shy | ○ | ○ | ○ |
| 87. Strips off clothes or throws away clothes | ○ | ○ | ○ |
| 88. Says he/she can do things that he/she is not capable of | ○ | ○ | ○ |
| 89. Stands too close to others | ○ | ○ | ○ |
| 90. Sees, hears, something which isn't there. Hallucinations | ○ | ○ | ○ |
| Please describe: |  |  |  |
| 91. Talks about or attempts suicide | ○ | ○ | ○ |
| 92. Talks too much or too fast | ○ | ○ | ○ |
| 93. Talks to self or imaginary people or objects | ○ | ○ | ○ |
| 94. Tells lies | ○ | ○ | ○ |
| 95. Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow | ○ | ○ | ○ |
| 96. Tense, anxious, worried | ○ | ○ | ○ |
| 97. Throws or breaks objects | ○ | ○ | ○ |
| 98. Tries to manipulate or provoke others | ○ | ○ | ○ |
| 99. Under-reacts to pain | ○ | ○ | ○ |
| 100. Unrealistically happy or elated | ○ | ○ | ○ |
| 101. Unusual body movements, posture, or way of walking | ○ | ○ | ○ |
| Please describe: |  |  |  |
| 102. Upset and distressed over small changes in routine or environment | ○ | ○ | ○ |
| Please describe: |  |  |  |
| 103. Urinates outside toilet, although toilet trained | ○ | ○ | ○ |
| 104. Very bossy | ○ | ○ | ○ |
| 105. Wanders aimlessly | ○ | ○ | ○ |
| 106. Whines and complains a lot | ○ | ○ | ○ |

|  | Not true as far as you know<br>0 | Somewhat or sometimes true<br>1 | Very true or often true<br>2 |
|---|---|---|---|
| 107. Overall, do you feel that your child has problems with feelings or behaviour, in addition to problems with development? If not, please tick the circle for 0. If so, but they're minor, please tick the circle for 1. If they're major problems, please tick the circle for 2 | ○ | ○ | ○ |

**Please write in any problems he/she has that were not listed above:** ______________________________

______________________________________________________________

______________________________________________________________

**Please feel free to make any further comments:** ______________________________

______________________________________________________________

______________________________________________________________

*Acknowledgement: Einfeld & Tonge, 1993*

**Can you please answer the following questions by ticking whether your son/ daughter displays these behaviours.**

|  |  | No | Sometimes | Yes, often |
|---|---|---|---|---|
| 1. | Does the young person have longstanding and severe overactivity and impulsive behaviours more than you would expect? | ☐ | ☐ | ☐ |
| 2. | Does this overactivity and impulsive behaviour occur at all times and in all settings? | ☐ | ☐ | ☐ |
| 3. | Does the young person appear unduly preoccupied/ suspicious or frequently misinterpret situations? | ☐ | ☐ | ☐ |
| 4. | Does the young person have odd behaviours or appear to respond to voices or see things that are not there? | ☐ | ☐ | ☐ |

*Acknowledgement: Steven and Raftery. 'Healthcare Needs Assessment', 1994.*

# PART 2

# YOUR FAMILY

**Instructions**

As you are aware, Down syndrome is more than a set of symptoms shown by a particular individual. It can have wide reaching effects on a family including the health of parents, communication between partners, needs for personal support, and stress levels. The questions in Part 2 ask about the experiences of families of young adults with Down syndrome, in order to gain an understanding of how families manage with a son/ daughter with Down syndrome, particularly as they enter adulthood.

We aim to identify areas of family life that are vulnerable to the experience of transition from school to adulthood for young people with Down syndrome, and promote them as being important when policies for the support and care of families with disabled children are developed.

These questions have been included after consultation with parents of children with Down syndrome and other disabilities. The questions have been widely used in research with the general population.

The following questions in Part 2 should be filled out by the MAIN CARER of the individual with Down syndrome, that is the person who provides most of his/her day-to-day care (if your child no longer lives at home with you, these questions should be filled out by the person who was previously the main carer when your son/ daughter lived at home). Please indicate the relationship of the main carer to the child or young adult with Down syndrome:

☐ Mother
☐ Father
☐ Foster Mother
☐ Foster Father
☐ Adoptive Mother
☐ Adoptive Father
☐ Stepmother
☐ Stepfather
☐ Other (please specify)________________________________

We hope that you will contact us if you have any queries about these questions.

# SECTION 1: FAMILY QUALITY OF LIFE

This section asks you to describe the way you experience your life together as a family. Please consider your family as those people who think of themselves as members of your family and who support and care for each other on a regular basis. What constitutes your family is a subjective judgment you are asked to make.

| **Please circle the response that best describes your level of satisfaction.**<br>**Please answer all questions in relation to the last 12 months.** | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|---|---|---|---|---|---|
| 1. My family enjoys spending time together | 1 | 2 | 3 | 4 | 5 |
| 2. My family members help the children learn to be independent | 1 | 2 | 3 | 4 | 5 |
| 3. My family has the support we need to relieve stress | 1 | 2 | 3 | 4 | 5 |
| 4. My family members have friends or others who provide support | 1 | 2 | 3 | 4 | 5 |
| 5. My family members help the children with schoolwork and activities | 1 | 2 | 3 | 4 | 5 |
| 6. My family members have transportation to get to the places they need to be | 1 | 2 | 3 | 4 | 5 |
| 7. My family members talk openly with each other | 1 | 2 | 3 | 4 | 5 |
| 8. My family members teach the children how to get along with others | 1 | 2 | 3 | 4 | 5 |
| 9. My family members have some time to pursue our own interests | 1 | 2 | 3 | 4 | 5 |
| 10. Our family solves problems together | 1 | 2 | 3 | 4 | 5 |
| 11. My family members support each other to accomplish goals | 1 | 2 | 3 | 4 | 5 |
| 12. My family members show that they love and care for each other | 1 | 2 | 3 | 4 | 5 |
| 13. My family has outside help available to us to take care of special needs of all family members | 1 | 2 | 3 | 4 | 5 |
| 14. Adults in our family teach the children to make good decisions | 1 | 2 | 3 | 4 | 5 |
| 15. My family gets medical care when needed | 1 | 2 | 3 | 4 | 5 |
| 16. My family has a way to take care of our expenses | 1 | 2 | 3 | 4 | 5 |
| 17. Adults in my family know other people in the childrens' lives (friends, teachers, etc.) | 1 | 2 | 3 | 4 | 5 |
| 18. My family is able to handle life's ups and downs | 1 | 2 | 3 | 4 | 5 |
| 19. Adults in my family have time to take care of the individual needs of every child | 1 | 2 | 3 | 4 | 5 |
| 20. My family gets dental care when needed | 1 | 2 | 3 | 4 | 5 |
| 21. My family feels safe at home, work, school, and in our neighbourhood | 1 | 2 | 3 | 4 | 5 |
| 22. My family member with a disability has support to accomplish goals at school or at workplace | 1 | 2 | 3 | 4 | 5 |
| 23. My family member with a disability has support to accomplish goals at home | 1 | 2 | 3 | 4 | 5 |
| 24. My family member with a disability has support to make friends | 1 | 2 | 3 | 4 | 5 |
| 25. My family has a good relationship with the service providers who work with our family member with a disability | 1 | 2 | 3 | 4 | 5 |

*Reference: Hoffman, L; Marquis ,J; Poston ,D; Summers, J.A; Turnbull ,A. (2006)*

# SECTION 2: FAMILY COMMUNICATION

The following questions ask about communication patterns in your family; they include everyday experience and times of greater intensity and times of decision-making.

**Please circle the response that best suits your answer.**

"Agree" means that while you do not "strongly agree" with the statement, you would tend to agree more often than disagree.

"Disagree" means that you would tend to disagree more often than you would agree with the statement.

| | Strongly agree | Agree | Disagree | Strongly disagree |
|---|---|---|---|---|
| 1. Planning family activities is difficult because we misunderstand each other | SA | A | D | SD |
| 2. In times of crisis we can turn to each other for support | SA | A | D | SD |
| 3. We cannot talk to each other about sadness we feel | SA | A | D | SD |
| 4. Individuals (in the family) are accepted for who they are | SA | A | D | SD |
| 5. We avoid discussing our fears and concerns | SA | A | D | SD |
| 6. We express feelings to each other | SA | A | D | SD |
| 7. There are lots of bad feelings in our family | SA | A | D | SD |
| 8. We feel accepted for who we are | SA | A | D | SD |
| 9. Making decisions is a problem in our family | SA | A | D | SD |
| 10. We are able to make decisions about how to solve problems | SA | A | D | SD |
| 11. We don't get on well together | SA | A | D | SD |
| 12. We confide in each other | SA | A | D | SD |

*Acknowledgement: Epstein, Baldwin, & Bishop, 1983*

# SECTION 3: SELF ASSESSMENT OF MOOD

Many things contribute to everyday moods and feelings. We would like a "snapshot" of your way of being in the last week.

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There is no right or wrong answer. Do not spend too much time on any statement.

| 0 = Did not apply to me at all<br>1 = Applied to me to some degree, or some of the time<br>2 = Applied to me a considerable degree, or a good part of the time<br>3 = Applied to me very much, or most of the time | Did not apply to me at all | Applied to me to some degree, or some of the time | Applied to me a considerable degree, or a good part of the time | Applied to me very much, or most of the time |
|---|---|---|---|---|
| 1. I found it hard to wind down | 0 | 1 | 2 | 3 |
| 2. I was aware of dryness in my mouth | 0 | 1 | 2 | 3 |
| 3. I couldn't seem to experience any positive feelings at all | 0 | 1 | 2 | 3 |
| 4. I experienced breathing difficulty (eg. excessively rapid breathing, breathlessness in the absence of physical exertion) | 0 | 1 | 2 | 3 |
| 5. I found it difficult to work up the initiative to do things | 0 | 1 | 2 | 3 |
| 6. I tended to over-react to situations | 0 | 1 | 2 | 3 |
| 7. I experienced trembling (eg. in the hands) | 0 | 1 | 2 | 3 |
| 8. I felt that I was using a lot of nervous energy | 0 | 1 | 2 | 3 |
| 9. I was worried about situations in which I might panic and make a fool of myself | 0 | 1 | 2 | 3 |
| 10. I felt that I had nothing to look forward to | 0 | 1 | 2 | 3 |
| 11. I found myself getting agitated | 0 | 1 | 2 | 3 |
| 12. I found it difficult to relax | 0 | 1 | 2 | 3 |
| 13. I felt down-hearted and blue | 0 | 1 | 2 | 3 |
| 14. I was intolerant of anything that kept me from getting on with what I was doing | 0 | 1 | 2 | 3 |
| 15. I felt I was close to panic | 0 | 1 | 2 | 3 |
| 16. I was unable to become enthusiastic about anything | 0 | 1 | 2 | 3 |
| 17. I felt that I wasn't worth much as a person | 0 | 1 | 2 | 3 |
| 18. I felt I was rather touchy | 0 | 1 | 2 | 3 |
| 19. I was aware of the action of my heart in the absence of physical exertion (eg. sense of heart rate increase, heart missing a beat) | 0 | 1 | 2 | 3 |
| 20. I felt scared without any good reason | 0 | 1 | 2 | 3 |
| 21. I felt that life was meaningless | 0 | 1 | 2 | 3 |

*Acknowledgement: Lovibond and Lovibond, 1993*

# SECTION 4: SELF ASSESSMENT OF PERSONAL HEALTH

The following questions ask for your assessment of your own health and wellbeing as parent/ carer of a young person with Down syndrome.

Answer every question by marking the circle that best fits your answer.
If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

| Excellent | Very good | Good | Fair | Poor |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much?

| | Yes, limited a lot | Yes, limited a little | No, not limited at all |
|---|---|---|---|
| 2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf: | ☐ | ☐ | ☐ |
| 3. Climbing several flights of stairs: | ☐ | ☐ | ☐ |

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| 4. Accomplished less than you would like: | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5. Were limited in the kind of work or other activities: | ☐ | ☐ | ☐ | ☐ | ☐ |

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| 6. Accomplished less than you would like: | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7. Didn't do work or other activities as carefully as usual: | ☐ | ☐ | ☐ | ☐ | ☐ |

**8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

| Not at all | A little bit | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

How much of the time during the past weeks.....

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| **9. Have you felt calm and peaceful?** | ☐ | ☐ | ☐ | ☐ | ☐ |
| **10. Did you have a lot of energy?** | ☐ | ☐ | ☐ | ☐ | ☐ |
| **11. Have you felt downhearted and blue?** | ☐ | ☐ | ☐ | ☐ | ☐ |

**12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**

| All of the time | Most of the time | Some of the time | A little bit of the time | None of the time |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**13. Please discuss the impact that having a child with Down syndrome has had on the health of the family. This may be mental, physical or any other aspect of health.**

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

*Acknowledgement: Ware, Kosinski and Keller, 1996*

# SECTION 5: INFORMAL ASSISTANCE NEEDS

**Listed below are 12 different types of assistance which people sometimes find helpful. These questions ask you to indicate how much you would like help in these areas.**

Please circle the response that best describes your needs. Please answer all questions.

| **To what extent do you feel a need for any of the following types of help or assistance?** | **Never** | **Once in a while** | **Sometimes** | **Often** | **Quite often** |
|---|---|---|---|---|---|
| 1. Someone to talk to about things that worry you | 1 | 2 | 3 | 4 | 5 |
| 2. Someone to help take care of your son/daughter | 1 | 2 | 3 | 4 | 5 |
| 3. Someone to talk to when you have questions about raising your son/daughter | 1 | 2 | 3 | 4 | 5 |
| 4. Someone who loans you money when you need it | 1 | 2 | 3 | 4 | 5 |
| 5. Someone who encourages you to keep going when things seem hard | 1 | 2 | 3 | 4 | 5 |
| 6. Someone who accepts your child regardless of how s/he acts | 1 | 2 | 3 | 4 | 5 |
| 7. Someone to help with household chores | 1 | 2 | 3 | 4 | 5 |
| 8. Someone to relax or joke with | 1 | 2 | 3 | 4 | 5 |
| 9. Someone to do things with your child | 1 | 2 | 3 | 4 | 5 |
| 10. Someone to provide you or your child with transportation | 1 | 2 | 3 | 4 | 5 |
| 11. Someone to deal with agencies or individuals when you cannot | 1 | 2 | 3 | 4 | 5 |
| 12. Someone who tells you about services for your child or family | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Dunst and Trivette, 1988*

**The following questions relates to the availability of support and assistance in your NEIGHBOURHOOD.**

**Do you know any of your neighbours well enough to do any of the following?**

Please tick yes or no for all statements.

| | Yes | No |
|---|---|---|
| Have your son/daughter minded for an hour in an emergency? | ☐ | ☐ |
| Have your son/daughter minded regularly? | ☐ | ☐ |
| Borrow $5 until you go to the bank? | ☐ | ☐ |
| Borrow something else? | ☐ | ☐ |
| Water the garden for you if you are away? | ☐ | ☐ |
| Feed your pets if you are away? | ☐ | ☐ |
| Have a talk with you if you are feeling down? | ☐ | ☐ |
| Get small items of shopping if you are ill? | ☐ | ☐ |
| Keep an eye on your home if you go away? | ☐ | ☐ |
| I live in an area where there are no neighbours nearby. | ☐ | ☐ |
| I have recently moved house. | ☐ | ☐ |

*Acknowledgement: Zubrick, Williams, Silburn and Vimpani, 2000*

# SECTION 6: AVAILABILITY OF TIME

**Caring for a SON/ DAUGHTER with Down syndrome may or may not place added demands on a parent's time. The following items ask whether you feel you have enough time to meet the needs of the family as a whole and also to meet your own individual requirements.**

For each item please circle the response that best describes how well the requirement is met on a consistent basis in your family (that is, month in and month out).

| **To what extent are the following resources adequate for you?** | **Does not apply** | **Not at all adequate** | **Seldom adequate** | **Sometimes adequate** | **Usually adequate** | **Almost always adequate** |
|---|---|---|---|---|---|---|
| 1. Time to get enough sleep/rest | N/A | 1 | 2 | 3 | 4 | 5 |
| 2. Time to be by yourself | N/A | 1 | 2 | 3 | 4 | 5 |
| 3. Time for family to be together | N/A | 1 | 2 | 3 | 4 | 5 |
| 4. Time to be with child(ren) | N/A | 1 | 2 | 3 | 4 | 5 |
| 5. Time to be with your spouse/partner | N/A | 1 | 2 | 3 | 4 | 5 |
| 6. Time to be with close friend(s) | N/A | 1 | 2 | 3 | 4 | 5 |
| 7. Time to socialize | N/A | 1 | 2 | 3 | 4 | 5 |
| 8. Time to keep in shape and look nice | N/A | 1 | 2 | 3 | 4 | 5 |
| 9. Time and money for travel/vacation | N/A | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Dunst et.al., 1988*

# SECTION 7: AGREEMENT WITH YOUR PARTNER

We are interested in the extent of agreement between you and your partner. "Partner" is the person with whom you have the most significant relationship. For example, partner could be a spouse, girl/boyfriend, parent or sibling.

I have a partner at present.

☐ Yes
☐ No

If you do not have a partner at present, please skip this section and go to Section 8.

Please circle the number that which best fits your answer.

1. Please indicate the approximate extent of agreement or disagreement between you and your partner for each of the following three items.

| | Always disagree | Almost always disagree | Frequently disagree | Occasionally disagree | Almost always agree | Always agree |
|---|---|---|---|---|---|---|
| 1. Philosophy of life | 0 | 1 | 2 | 3 | 4 | 5 |
| 2. Aims, goals and things believed to be important | 0 | 1 | 2 | 3 | 4 | 5 |
| 3. Amount of time spent together | 0 | 1 | 2 | 3 | 4 | 5 |

2. How often would you say the following events occur between you and your partner?

| | Never | Less than once a month | Once or twice a month | Once or twice a week | Once a day | More often |
|---|---|---|---|---|---|---|
| 4. Have a stimulating conversation | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. Calmly discuss something | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. Work together on a project | 0 | 1 | 2 | 3 | 4 | 5 |

3. The dots on the following line represent different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness in most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

| 0 | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| Extremely unhappy | Fairly unhappy | A little unhappy | Happy | Very happy | Extremely happy | Perfect |
| ○ | ○ | ○ | ○ | ○ | ○ | ○ |

*Acknowledgement: Sharpley and Rogers, 1984*

# SECTION 8: FAMILY AND COMMUNITY SUPPORT

**Listed below are people and groups that are often helpful to members of a family with a son/daughter with Down syndrome. The following questions ask you to indicate how helpful each source is to your family.**

Please circle the response that best describes how helpful the sources have been to your family **during the past 3-6 months**. If a source of help has not been available to your family during this period of time, circle N/A (Does not apply)

| **How helpful has each of the following been to you in terms of raising your son/daughter with Down syndrome?** | Does not apply | Not at all helpful | Sometimes helpful | Generally helpful | Very helpful | Almost always helpful |
|---|---|---|---|---|---|---|
| 1. My parents | N/A | 1 | 2 | 3 | 4 | 5 |
| 2. My spouse or partner's parents | N/A | 1 | 2 | 3 | 4 | 5 |
| 3. My relatives | N/A | 1 | 2 | 3 | 4 | 5 |
| 4. My spouse or partner's relatives | N/A | 1 | 2 | 3 | 4 | 5 |
| 5. Spouse or partner | N/A | 1 | 2 | 3 | 4 | 5 |
| 6. My friends | N/A | 1 | 2 | 3 | 4 | 5 |
| 7. My spouse or partner's friends | N/A | 1 | 2 | 3 | 4 | 5 |
| 8. My own children | N/A | 1 | 2 | 3 | 4 | 5 |
| 9. Other parents | N/A | 1 | 2 | 3 | 4 | 5 |
| 10. Co-workers | N/A | 1 | 2 | 3 | 4 | 5 |
| 11. Parent groups | N/A | 1 | 2 | 3 | 4 | 5 |
| 12. Social groups/clubs | N/A | 1 | 2 | 3 | 4 | 5 |
| 13. Members of church or religious group/ minister or leader | N/A | 1 | 2 | 3 | 4 | 5 |
| 14. My family or son's/daughter's physician | N/A | 1 | 2 | 3 | 4 | 5 |
| 15. Early childhood intervention program | N/A | 1 | 2 | 3 | 4 | 5 |
| 16. Play group/school/day-care centre | N/A | 1 | 2 | 3 | 4 | 5 |

*Acknowledgement: Dunst, Jenkins and Trivette, 1988*

# QUESTIONNAIRE FEEDBACK

**1. Did you find any of the questions confusing or difficult to answer?**

☐ No – please go to Question 2

☐ Yes – please describe which question in the space below

________________________________________

________________________________________

________________________________________

**2. Did you find any of the questions upsetting?**

☐ No – please go to Question 3

☐ Yes – please describe which question in the space below

________________________________________

________________________________________

________________________________________

**3. Are there any other questions or topics you think we should have included?**

☐ No

☐ Yes – please make any suggestions in the space below

________________________________________

________________________________________

________________________________________

**4. How long did it take you to complete the questionnaire?** ______________________

**5. Did you hear about this study before receiving this questionnaire in the mail?**

If yes, how did you hear about it?

________________________________________

________________________________________

________________________________________

**If you have any further comments about this questionnaire, this research or anything else that you would like to tell us about, please make them in the space below.**

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

______________________________________________

**Thank you so much for taking the time to complete the questionnaire.**

**We appreciate your generous contribution to Down syndrome research.**

Please return this questionnaire and the consent form in the Reply Paid envelope:

Down Syndrome Transition Study
Telethon Institute for Child Health Research
PO Box 855
WEST PERTH WA 6872

## Appendix E: Literature categorized by type of research, country, level of evidence and topic

| Author, year | Title | Research article |  |  | Report | Book | Country | Level of Evidence | Topic |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  | Quantitative | Qualitative | Opinion |  |  |  |  | ICF | Transition | ID |
| May, 2000 | Transition and change in the lives of people with intellectual disabilities |  |  |  |  | X | UK | NA |  | X | X |
| Hudson, 2003 | From adolescence to young adulthood: the partnership challenge for learning disability services in England |  |  | X |  |  | UK | V |  | X | X |
| Michaels et al., 2005 | Collaboration and consultation in transition planning |  |  | X |  |  | US | V |  | X |  |
| Caton et al., 2006 | Tracking post-school destinations of young people with mild intellectual disabilities: the problem of attrition |  | X |  |  |  | UK |  |  | X | X |
| Clegg et al., 2001 | Severe intellectual disability and transition to adulthood |  | X |  |  |  | UK | IV |  | X | X |
| World Health Organization, 2001 | International classification of functioning disability and health |  |  |  |  | X | Europe |  | X |  |  |
| World Health Organization, 2007 | International classification of functioning disability and health – children and youth |  |  |  |  | X | Europe |  | X |  |  |
| Stucki, 2005 | International classification of functioning, disability, and health (ICF): a promising framework and classification for rehabilitation medicine |  |  | X |  |  | Europe | V | X |  |  |
| National Health and Medical Research Council, 2009 | NHMRC levels of evidence and grades for recommendations for developers of guidelines |  |  |  | X |  | AUS | NA |  |  |  |
| Schalock et | The renaming of mental retardation: |  |  | X |  |  | US | V |  |  | X |

| Author, year | Title | Research article |  |  | Report | Book | Country | Level of Evidence | Topic |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  | Quantitative | Qualitative | Opinion |  |  |  |  | ICF | Transition | ID |
| al., 2007 | understanding the change to the term intellectual disability |  |  |  |  |  |  |  |  |  |  |
| Wen, 1997 | The definition and prevalence of intellectual disability in Australia. |  |  |  | X |  | AUS | NA |  |  | X |
| Schalock et al., 2010 | Intellectual Disability: Definition, Classification, and Systems of Supports |  |  |  |  | X | US | NA |  |  | X |
| Van Naarden Braun et al., 2006 | A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: the acquisition of adult social roles | X |  |  |  |  | US | IV |  |  | X |
| Leonard et al., 2003 | Prevalence of intellectual disability in Western Australia | X |  |  |  |  | AUS | IV |  |  | X |
| Leonard et al., 2004 | Inaugural Report of the IDEA Database- Intellectual Disability in Western Australia |  |  |  | X |  | AUS | NA |  |  | X |
| Developmental Disability Steering Group, 2005 | Management Guidelines: Developmental Disability Version 2 |  |  |  | X |  | AUS | NA |  |  | X |
| Emerson, 2003 | Prevalence of psychiatric disorders in children and adults with and without Intellectual disability | X |  |  |  |  | UK | IV |  |  | X |
| Blacher, 2001 | Transition to adulthood: mental retardation, families, and culture |  |  | X |  |  | US | V |  | X |  |
| Dyke et al., 2007 | Down syndrome Needs Opinion Wishes Study Report |  |  |  | X |  | AUS | NA |  |  | X |
| Van Naarden Braun et.al., 2009 | Activity limitations among young adults with developmental disabilities: A population-based follow-up study | X |  |  |  |  | US | IV |  |  | X |

| Author, year | Title | Research article |  |  | Report | Book | Country | Level of Evidence |  | Topic |  |
|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  | Quantitative | Qualitative | Opinion |  |  |  |  | ICF | Transition | ID |
| Eagar et al., 2006 | Functional assessment to predict capacity for work in a population of school-leavers with disabilities | X |  |  |  |  | AUS | IV |  |  | X |
| Williams et al., 1997 | Effects of leisure education on self-determination, social interaction, and positive affect of young adults with mental retardation |  | X |  |  |  | UK | V |  |  | X |
| Cory et al., 2006 | Effects of a leisure education program on social knowledge and skills of youth with cognitive disabilities | X |  |  |  |  | US | IV |  |  | X |
| Devine et al., 2000 | Social acceptance and leisure lifestyles of people with disabilities |  |  | X |  |  | UK | V |  |  | X |
| Duvdevany et al., 2004 | Leisure activities, friendships, and quality of life of persons with intellectual disability: foster homes vs community residential settings | X |  |  |  |  | Israel | IV |  |  | X |
| Oates et.al., 2009 | Leisure participation for school-aged children with Down syndrome | X |  |  |  |  | AUS | IV |  |  | X |
| McVilly et.al., 2006 | "I get by with a little help from my friends": Adults with intellectual disability discuss loneliness |  | X |  |  |  | AUS | IV |  |  | X |
| Hughes, 2001 | Transition to adulthood: Supporting young adults to access social, employment, and civic pursuits |  |  | X |  |  | US | V |  | X |  |
| Ryan et al., 2000 | Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being |  |  | X |  |  | US | V |  |  |  |
| Van Cleve et al., 2006 | Part II: clinical practice guidelines for adolescents and young adults with Down syndrome: 12 to 21 years |  |  | X |  |  | US | V |  |  | X |
| Shaddock et al., 2000 | Walking the Talk" about self-determination |  |  |  |  | X | UK | NA |  |  | X |

| Author, year | Title | Research article | | | Report | Book | Country | Level of Evidence | ICF | Topic | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Quantitative | Qualitative | Opinion | | | | | | Transition | ID |
| Laragy, 2004 | Self-determination within Australian school transition programmes for students with a disability | | | X | | | AUS | V | | X | |
| Halpern, 1999 | Transition: is it time for another re-bottling. 1999 Annual OSEP Project Directors' Meeting’ | | | | X | | US | NA | | X | |
| Halloran, 1993 | Transition services requirement: issues, implication, challenges | | | | | X | US | NA | | X | |
| Wehmen, 1993 | Transition from school to adult-hood for young people with disabilities: critical issues and policies | | | | | X | US | NA | | X | |
| Lachapelle et al., 2005 | The relationship between quality of life and self-determination: an international study | | X | | | | Canada | IV | | | X |
| Agran et. al., 2000 | Promoting transition goals and self-determination through student self-directed learning: The self-determined learning model of instruction | X | | | | | US | IV | | X | X |
| Wehmeyer et al, 1998 | The relationship between self-determination, quality of life, and life satisfaction for adults with mental retardation | X | | | | | US | IV | | | X |
| Wehmeyer et al., 2003 | The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning | X | | | | | US | IV | | | X |
| Wehmeyer et al., 2003 | Adult outcomes for students with cognitive disabilities three-years after high-school: The impact of self- | X | | | | | US | IV | | | X |

| Author, year | Title | Research article | | | Report | Book | Country | Level of Evidence | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Quantitative | Qualitative | Opinion | | | | | ICF | Transition | ID |
| | determination | | | | | | | | | | |
| Stancliffe et al., 2000 | Substitute decision-making and personal control: Implications for self-determination | X | | | | | US | IV | | | X |
| Grigal et al., 2003 | Self-determination for students with disabilities: Views of parents and teachers | X | | | | | US | IV | | | X |
| Wehmeyer et al., 1997 | Self-determination and positive adult outcomes: a follow-up study of youth with mental retardation or learning disabilities | X | | | | | US | IV | | | X |
| Wehmeyer et al., 2001 | Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments | X | | | | | US | IV | | X | |
| Gil, 2007 | Bridging the transition gap from high-school to college: Preparing students with disabilities and their families | | | X | | | US | V | | X | |
| Duvdevany et al., 2002 | Self-determination and mental retardation: is there an association with living arrangement and lifestyle satisfaction | X | | | | | Israel | IV | | | X |
| Sandys, 2003 | Work and employment for people with developmental disabilities | | | | | X | Canada | NA | | | |
| Gosling et al., 2000 | An employment project as a route to social inclusion for people with learning difficulties | | | X | | | UK | V | | | X |
| Lemon et al., 2003 | Community based cooperative ventures for adults with intellectual disabilities | | | X | | | Canada | | | | X |
| Wehman et al., 1997 | Transition into supported employment for young adults with | | | X | | | US | V | | X | |

| Author, year | Title | Research article |  |  | Report | Book | Country | Level of Evidence | Topic |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  | Quantitative | Qualitative | Opinion |  |  |  |  | ICF | Transition | ID |
|  | severe disabilities: Current practices and future directions |  |  |  |  |  |  |  |  |  |  |
| Mank et al., 2003 | Supported employment outcomes across a decade: Is there evidence of improvement in the quality of implementation? | X |  |  |  |  | US | IV |  |  |  |
| Mank, 1996 | Natural support in employment for people with disabilities: What do we know and when did we know it? |  |  | X |  |  | US | V |  |  | X |
| Hyde, 1998 | Sheltered and supported employment in the 1990's | X | X |  |  |  | UK | IV |  |  |  |
| Stephens et al., 2005 | A longitudinal study of employment and skill acquisition among individuals with developmental disabilities | X |  |  |  |  | US | IV |  |  |  |
| Wistow et al., 2003 | Users views of supported employment and social inclusion: a qualitative study of 30 people in work |  | X |  |  |  | UK | IV |  |  | X |
| Jahoda et al., 2008 | Feelings about work: a review of the socio-emotional impact of supported employment on people with intellectual disabilities |  |  | X |  |  | UK | V |  |  | X |
| Banks et al., 2010 | Supported employment for people with intellectual disability: the effects of job breakdown on psychological well-being |  | X |  |  |  | UK | IV |  | X | X |
| Roulstone et al., 2005 | Working futures: disabled people, policy and social inclusion |  |  |  |  | X | US | NA |  |  |  |
| Winn et al., 2009 | Transition from school for youth with a disability: issues and challenges |  |  | X |  |  | AUS | V |  | X |  |
| Davies et al., 2009 | Transitions from school for young adults with intellectual disability: Parental perspectives on 'life |  X | X |  |  |  | AUS | IV |  | X | X |

| Author, year | Title | Research article | | | Report | Book | Country | Level of Evidence | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Quantitative | Qualitative | Opinion | | | | | ICF | Transition | ID |
| | adjustment' | | | | | | | | | | |
| Kraemer et al., 2001 | Transition for young adults with severe mental retardation: school preparation, parent expectations, and family involvement | X | | | | | US | IV | | X | X |
| Brown et al.,2006 | The quest for ordinary lives: the integrated post-school vocational functioning of 50 workers with significant disabilities | | | X | | | US | V | | X | X |
| Williams et al., 1997 | Effects of leisure education on self-determination, social interaction, and positive affect of young adults with mental retardation | | X | | | | US | IV | | | X |
| Hoge et al., 1995 | Recreation participation patterns of adults with and without mental retardation | | X | | | | US | IV | | | X |
| Dattilo et al., 1994 | Understanding leisure services for individuals with mental retardation | | | X | | | Athens | V | | | X |
| Mactavish et al., 2004 | Re-injecting spontaneity and balance in family life: parents' perspectives on recreation in families that include children with developmental disability | X | X | | | | US | IV | | | X |
| Van Naarden Braun et al., 2006 | Factors associated with leisure activity among young adults with developmental disabilities | | X | | | | US | IV | X | | X |
| Weiss et al., 2003 | Virtual reality provides leisure time opportunities for young adults with physical and intellectual disabilities | | X | | | | Israel | IV | | | X |
| Li et al., 2006 | Successful experience of people with Down syndrome | | X | | | | HK | IV | | | X |
| Buttimer et al., 2005 | Patterns of leisure participation among adolescents with a mild | | X | | | | UK | IV | | | X |

| Author, year | Title | Research article |  |  | Report | Book | Country | Level of Evidence | Topic |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  | Quantitative | Qualitative | Opinion |  |  |  |  | ICF | Transition | ID |
|  | intellectual disability |  |  |  |  |  |  |  |  |  |  |
| Specht et al., 2002 | The importance of leisure in the lives of persons with congenital physical disabilities |  | X |  |  |  | Canada | IV |  |  | X |
| Harmon et al., 1998 | Transition from adolescence to early adulthood: Adaptation and psychiatric status of women with 47,XXX |  | X |  |  |  | US | IV |  | X | X |
| Australian Institute of Health and Welfare, 2006 | Disability rates among Aboriginal and Torres Strait Islander people: updating the Indigenous factor in disability services performance indicator denominators |  |  |  | X |  | AUS | NA |  |  | X |
| Esbensen et al., 2007 | Factors predicting mortality in midlife adults with and without Down syndrome living with family | X |  |  |  |  | US | IV |  |  | X |
| Kobe et al., 1994 | Parenting stress and depression in children with mental retardation and developmental disabilities | X |  |  |  |  | US | IV |  |  | X |
| Ward et al., 2003 | Transition: the experiences of young people with learning disabilities and their families in England |  | X |  |  |  | UK | IV |  | X | X |
| Blackorby et al., 1996 | Longitudinal postschool outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study | X |  |  |  |  | US | IV |  | X | X |
| Kraemer et al., 2003 | Quality of life for young adults with mental retardation during transition | X | X |  |  |  | US | IV |  | X | X |
| Huber et al., 2010 | Personal perception and personal factors: incorporating health-related quality of life into the International classification of functioning, disability and health |  |  | X |  |  | Canada | V | X |  |  |

| Author, year | Title | Research article |  |  | Report | Book | Country | Level of Evidence | Topic |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  | Quantitative | Qualitative | Opinion |  |  |  |  | ICF | Transition | ID |
| Kober et al., 2005 | The effect of different types of employment on quality of life | X | X |  |  |  | NZ | IV |  |  | X |
| Seltzer et al., 2001 | Quality of life of adults with mental retardation/ developmental disabilities who live with family |  |  | X |  |  | US | V |  |  | X |
| McIntyre et al., 2004 | Quality of life for young adults with severe intellectual disability: mothers' thoughts and reflections |  | X |  |  |  | US | IV |  | X | X |
| Hanley-Maxwell et al., 1995 | The second shock: a qualitative study of parents perspectives and needs during their child's transition from school to adult life |  | X |  |  |  | US | IV |  | X | X |
| Read, 2000 | Disability, the Family and Society: Listening to Mothers |  |  |  |  | X | US | NA |  |  |  |
| Kohler et al., 2003 | Transition-focused education: Foundations for the future |  |  | X |  |  | US | V |  | X |  |
| Knox et al., 2000 | Family control: The views of families who have a child with an intellectual disability |  |  | X |  |  | AUS | IV |  |  | X |
| Timmons et al., 2004 | Managing service delivery systems and the role of parents during their children's transitions |  | X |  |  |  | US | IV |  | X |  |
| Schneider et al., 2006 | Families challenged by and accommodating to the adolescent years |  | X |  |  |  | AUS | IV |  |  | X |
| Hendey et al., 2002 | Disability and transition to adulthood: achieving independent living |  | X |  |  | X | UK | NA |  | X |  |
| Pownceby et al., 1997 | The Coming of Age Project: A Study of the Transition from Pediatric to Adult Care and Treatment Adherence amongst Young People with Cystic Fibrosis. |  |  |  |  | X | UK | NA |  | X |  |

| Author, year | Title | Research article | | | Report | Book | Country | Level of Evidence | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Quantitative | Qualitative | Opinion | | | | | ICF | Transition | ID |
| Morris, 2002 | Moving into Adulthood: Young People Moving into Adulthood | | | | | X | UK | NA | | X | |
| Roizen, 2007 | Down syndrome. In: Batshaw ML, Pellegrino L, Roizen NJ, editors. Children with Disabilities | | | | | X | US | NA | | | X |
| Thomson et al., 1995 | The transition to adulthood for children with Down syndrome | | X | | | | UK | V | | X | X |
| Pascal et al., 2004 | Disability and transition to adulthood: the politics of parenting | | X | | | | UK | IV | | X | X |
| Mill et al., 2009 | Negotiating autonomy within the family: the experiences of young adults with intellectual disabilities | | X | | | | AUS | IV | | X | X |
| Carr, 1994 | Annotation: Long term outcome for people with Down's syndrome | | | X | | | UK | V | | X | X |
| Redmund, 1996 | Listening to parents: the aspirations, expectations and anxieties of parents about their teenager with learning disabilities | | | | | X | UK | NA | | | X |
| Smyth et al., 2003 | Future aspirations of students with severe learning disabilities and of their parents on leaving special schooling | | X | | | | UK | IV | | X | X |
| McConkey et al., 2002 | Parental perceptions of risks with older teenagers who have severe learning difficulties contrasted with the young people's views and experiences | | X | | | | UK | IV | | X | X |
| Gillan et al., 2010 | Transition from special education into postschool services for young adults with intellectual disability: Irish parents' experience | | X | | | | UK | IV | | X | X |
| Heslop et al., | Bridging the Divide at Transition: | | | | X | | UK | NA | | X | X |

| Author, year | Title | Research article | | | Report | Book | Country | Level of Evidence | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Quantitative | Qualitative | Opinion | | | | | ICF | Transition | ID |
| 2002 | What Happens for Young People with Learning Difficulties and their Families | | | | | | | | | | |
| Cameron et al., 2002 | Enabling young people with a learning disability to make choices at a time of transition | X | | | | | UK | IV | | X | X |
| Tarleton et al., 2005 | Changes and choices: finding out what information young people with learning disabilities, their parents and supporters need at transition | | X | | | | UK | IV | | X | X |
| Mank et al., 1998 | Employment outcomes for people with severe disabilities: opportunities for improvement | X | | | | | US | IV | | | X |
| Betz, 2007 | Facilitating the transition of adolescents with developmental disabilities: Nursing practice issues and care | | | X | | | US | V | | X | X |
| Morris, 1999 | 'Hurtling into a Void': Transition to adulthood for young people with complex health and support needs | | | | | X | UK | NA | | X | |
| US Department of Education, 2006 | Assistant to States for the Education of Children with Disabilities and Preschool Grants for Children with Disabilities | | | | X | | US | NA | | | X |
| Keogh et al., 2004 | Children with developmental delays twenty years later: Where are they? How are they? | X | X | | | | US | IV | | | X |
| Gallivan-Fenlon, 1994 | “Their senior year": Family and service provider perspectives on the transition from school to adult life for young adults with disabilities | | X | | | | US | | | X | X |
| Murray, 2007 | Families' care work during the transition from school to post-school | | X | | | | AUS | IV | | X | X |

| Author, year | Title | Research article | | | Report | Book | Country | Level of Evidence | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Quantitative | Qualitative | Opinion | | | | | ICF | Transition | ID |
| | for children with severe disabilities | | | | | | | | | | |
| Burrows et al., 2001 | The post school outcomes of young adults with autism spectrum disorder | X | | | | | AUS | V | | X | X |
| Smart, 2004 | Transition planning and the needs of young people and their carers: the alumni project | X | X | | | | UK | IV | | X | X |
| Hudson, 2006 | Making and missing connections: learning disability services and the transition from adolescence to adulthood | | | X | | | UK | V | | X | X |
| Parmenter et al., 1991 | Transition education: a pilot program for students with disabilities in transition in the NSW Department of School Education | | | | X | | AUS | NA | | X | |
| Pilnick et al., 2011 | Just being selfish for my own sake...' balancing the views of young adults with intellectual disabilities and their carers in transition planning | | X | | | | UK | V | | X | X |
| Rapley, 2004 | The Social Construction of Intellectual Disability | | | | | X | UK | NA | | | X |
| Geyh et al., 2007 | Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): a systematic review | | | X | | | Europe | IV | X | | |
| Sakzewaski et al., 2007 | Clinometric properties of participation measures for 5-to 13-year-old children with cerebral palsy: a systematic review | | | X | | | AUS | | X | | X |
| Swanson et al., 2003 | Comparing disability survey questions in five countries: a study using the ICF | | | X | | | US | V | X | | |

| Author, year | Title | Research article | | | Report | Book | Country | Level of Evidence | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Quantitative | Qualitative | Opinion | | | | | ICF | Transition | ID |
| | to guide comparisons | | | | | | | | | | |
| Kennedy, 2002 | In: Federal activities related to the World Health Organization's international classification of functioning, disability and health | | | | X | | US | NA | X | | |
| Madden et al., 2003 | The ICF as a framework for national data: The introduction of ICF into Australian data dictionaries | | | X | | | AUS | V | X | | |
| Mbogoni, 2003 | On the application of the ICIDH and ICF in developing countries: Evidence from the United Nations Disability Statistics Database (DISTAT) | | | X | | | US | V | X | | |
| Arthanat et al., 2004 | The international classification of functioning, disability and health and its application to cognitive disorders | | | X | | | US | V | X | | X |
| Battaglia et al., 2004 | International classification of functioning, disability and health in a cohort of children with cognitive, motor, and complex disabilities | X | | | | | Europe | IV | X | | X |
| Rosenbaum et al., 2004 | The World Health Organization international classification of functioning, disability and health: A model to guide clinical thinking, practise, and research in the field of cerebral palsy | | | X | | | Canada | V | X | | X |
| Butcher et al., 2008 | Stuck in transition? Exploring the spaces of employment training for youth with intellectual disability | | X | | | | Canada | IV | | X | X |
| Beresford, 2004 | On the road to nowhere? Young disabled people and transition | | | X | | | UK | V | | X | X |

| Author, year | Title | Research article |  |  | Report | Book | Country | Level of Evidence | Topic |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  | Quantitative | Qualitative | Opinion |  |  |  |  | ICF | Transition | ID |
| King et al., 2007 | A framework of operating models for interdisciplinary research programs in clinical service organizations |  |  | X |  |  | UK | V |  | X |  |

Appendix F: Journal article published in Disability and Rehabilitation

*Disability & Rehabilitation*, 2012; 34(20): 1747–1764
© 2012 Informa UK, Ltd.
ISSN 0963-8288 print/ISSN 1464-5165 online
DOI: 10.3109/09638288.2012.660603

PERSPECTIVES IN REHABILITATION

# Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF

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*Purpose*: The purpose of this review was to describe literature relating to transition for young people with an intellectual disability and identify gaps within the current knowledge base. *Method*: A narrative literature review was undertaken. Searches of databases Medline, CINAHL, PsycINFO, ERIC, ISI Web of Science and ProQuest 500 International provided relevant research articles. The search terms used were intellectual disability, transition, employment, and ICF as well as other terms derived from the ICF. Manual searches of reference lists identified additional studies. Furthermore, government websites were searched for relevant reports and policies. *Results*: Transition literature was explored by ICF domains; body functions and structures, activity and participation and contextual factors. Studies were identified in some but not all areas and included literature describing self-determination and participation in leisure activities for those with mild intellectual disability. However, significant gaps were found particularly for those with severe intellectual disability. *Conclusions*: The ICF is a useful tool in framing a review of transition literature for young people with intellectual disability due to the complexity and multi-faceted nature of transition. The important influence of environmental factors including family systems, post-school services and access to transport were highlighted as having considerable impacts on transition outcomes.

**Keywords:** Transition, intellectual disability, school, ICF, employment

**Implications for Rehabilitation**

- The ICF is a useful tool in framing transition research to identify gaps.
- The current body of literature in transition from school for young adults with intellectual disabilities is too singularly focused and rarely considers those with moderate to severe intellectual disability.
- There has been little research on this topic in low and middle income countries.
- The scale of the impact of environmental factors on young people transitioning from school to post-school is currently under-represented.
- A holistic approach to post-school outcomes needs to be undertaken in future research.

## Introduction

The term transition has been commonly used to describe the crucial task of moving from the protected life of a child to the autonomous and independent life of an adult. Individuals vary substantially in their experiences and the rate at which they transition. The transition of adolescents with an intellectual disability is characterised by wider scope, longer duration, and attenuated experiences than for those without an intellectual disability [1–3]. Transition has been reported by families and caregivers as a time of upheaval, stress and important decisions, and there is much confusion about services available [4]. Challenges which research into transition is yet to overcome include the bias towards people with mild intellectual disability, accurately describing the psychological experience of transition, and the strong focus on employment and autonomy alone [5]. Exploring and facilitating the complex and multi-faceted transition process for young people with intellectual disabilities has now become an important concern internationally for service providers and researchers working within this area.

The International Classification of Functioning, Disability and Health (ICF) presents a framework that provides a scientific basis and standardised language for describing and classifying health domains, health-related

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*(Accepted January 2012)*

states and health outcome measurement [6]. More recently, the Children and Youth Version (ICF-CY) was developed, extending this framework for younger age ranges [7]. The ICF framework encompasses three components. Body functions and structures, describes the anatomical parts and physiological functioning of a person. Loss of physiological functioning or damaged body structures are referred to as "impairments." The second component of the ICF, activity, refers to the execution of a task and the ease with which this is done. Issues with completing a task or activity are described as "activity limitations." The third component describes involvement in a life situation, or participation with difficulties described as "participation restrictions" [7,8]. These three components are classed within the umbrella terms of functioning and disability. The impact of contextual factors, both environmental and personal factors, are also considered within the framework.

The aim of this review was to describe current literature relating to transition for young people with an intellectual disability and highlight the weaknesses and gaps within the current knowledge base. The specific goals of this review were to: (1) employ the ICF as a framework to holistically describe transition literature, (2) describe transition issues internationally and evaluate the similarities and differences in Australia, (3) describe changes in transition policy and services over time and identify impacts on outcomes, and (4) evaluate and describe the methodological challenges in transition research with young adults with intellectual disability.

## Methods

A narrative literature review was undertaken due to the paucity of research in this area. To locate literature relevant to the purpose of this review the databases Medline (1966–2011), CINAHL (1982–2011), PsycINFO (1920–2011), ERIC (1992–2011), ISI Web of Science (1992–2011), and ProQuest 500 International (1938–2011) were searched from their earliest records to most recent. The search terms used were intellectual disability, transition, employment, and ICF as well as other search terms derived from the ICF. These were truncated, exploded and adjusted to achieve optimal results. Manual searches of reference lists of relevant articles were conducted to identify further studies. In addition, government websites were searched for relevant reports and policies. Studies were included in the review if they involved participants who had an intellectual disability. Outcomes of interest were those relating to the domains of the ICF, body functions and structures, activity and participation and contextual factors. The primary source of references for this review was research articles. Refer to Table I for description of literature by type, country, level of evidence (guided by NHMRC [9]) and topic.

## Results

All of the research articles in this review were rated as level four ($n=61$, 63.5%) or five ($n$-35, 36.5%) on the level of evidence classifications as guided by the National Health and Medical Research Council [9]. None of the literature reached a higher level of evidence. Thirty-five articles were opinion or comment pieces (27.3%), 34 were quantitative (26.6%) and 37 were qualitative (28.9%) articles. The majority of literature identified for this review emerged from the United States (US; 42.2%), followed by the United Kingdom (UK; 27.3%) and then Australia (16.4%) (Table II).

Table I. Description of literature by type, country, level of evidence* and topic.

| Description of Literature | $n$ | % |
|---|---|---|
| Type of Literature | | |
| Book | 17 | 13.3 |
| Government/Agency Report | 11 | 8.6 |
| Articles | | |
| Quantitative | 34 | 26.6 |
| Qualitative | 37 | 28.9 |
| Mixed methods (quantitative and qualitative) | 6 | 4.7 |
| Opinion/comment | 35 | 27.3 |
| Total | 128 | 100 |
| Countries | | |
| UK | 35 | 27.3 |
| AUS | 21 | 16.4 |
| US | 54 | 42.2 |
| Europe | 6 | 4.7 |
| Canada | 7 | 5.5 |
| Other | 5 | 3.9 |
| Total | 128 | 100 |
| Level of Evidence | | |
| IV | 61 | 63.5 |
| V | 35 | 36.5 |
| Total | 96 | 100 |
| Topics | | |
| Intellectual Disability and Transition | 34 | 26.6 |
| ICF | 14 | 10.9 |
| Intellectual disability only | 52 | 40.6 |
| Transition only | 19 | 14.8 |
| Other | 9 | 7.0 |
| Total | 128 | 100 |

*Note. Level of evidence as adapted from National Health and Medical Research Council. In: NHMRC levels of evidence and grades for recommendations for developers of guidelines. 2009 Australian Government.

### Body functions and structures

The body functions and structures component of the ICF describes impairments of physiological functions as well as psychological functioning. Impairments of mental cognition and functions are termed intellectual disability, and result from a range of underlying pathological processes. In 2007 the term "intellectual disability" was adopted by the American Association on Intellectual and Developmental Disabilities and is now widely recognised as the most appropriate term and henceforth will be used in this paper [10]. In the ICF, intellectual disability is classified as an intellectual function, together with intellectual growth, intellectual retardation and dementia, while theoretically excluding higher level cognitive functions and memory [6].

The statistical definition of intellectual disability employs comparison of an individual's performance to the performance

Table II. Literature categorized by type of research, country, level of evidence and topic.

| | | | Research article | | | | | | | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Ref. | Author, year | Title | Quantitative | Qualitative | Opinion | Report | Book | Country | Level of evidence[a] | ICF | Transition | Intel Dis |
| 1 | May, 2000 | Transition and change in the lives of people with intellectual disabilities | | | | | X | UK | NA | | X | X |
| 2 | Hudson, 2003 | From adolescence to young adulthood: the partnership challenge for learning disability services in England | | | X | | | UK | V | | X | X |
| 3 | Michaels et al., 2005 | Collaboration and consultation in transition planning | | | X | | | US | V | | X | |
| 4 | Caton et al., 2006 | Tracking post-school destinations of young people with mild intellectual disabilities: the problem of attrition | | X | | | | UK | | | X | X |
| 5 | Clegg et al., 2001 | Severe intellectual disability and transition to adulthood | | X | | | | UK | IV | | X | X |
| 6 | World Health Organization, 2001 | International Classification of Functioning Disability and Health | | | | | X | Europe | | X | | |
| 7 | World Health Organization, 2007 | International Classification of Functioning Disability and Health – Children and Youth | | | | | X | Europe | | X | | |
| 8 | Stucki, 2005 | International Classification of Functioning, Disability, and Health (ICF): a promising framework and classification for rehabilitation medicine | | | X | | | Europe | V | X | | |
| 9 | National Health and Medical Research Council, 2009 | NHMRC levels of evidence and grades for recommendations for developers of guidelines | | | | X | | AUS | NA | | | |
| 10 | Schalock et al., 2007 | The renaming of mental retardation: understanding the change to the term intellectual disability | | | X | | | US | V | | | X |
| 11 | Wen, 1997 | The definition and prevalence of intellectual disability in Australia | | | | X | | AUS | NA | | | X |
| 12 | Schalock et al., 2010 | Intellectual disability: definition, classification, and systems of supports | | | | | X | US | NA | | | X |
| 13 | Van Naarden Braun et al., 2006 | A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: the acquisition of adult social roles | X | | | | | US | IV | | | X |
| 14 | Leonard et al., 2003 | Prevalence of intellectual disability in Western Australia | X | | | | | AUS | IV | | | X |
| 15 | Leonard et al., 2004 | Inaugural report of the IDEA database- intellectual disability in Western Australia | | | | X | | AUS | NA | | | X |
| 16 | Developmental Disability Steering Group, 2005 | Management guidelines: developmental disability version 2 | | | | X | | AUS | NA | | | X |
| 17 | Emerson, 2003 | Prevalence of psychiatric disorders in children and adults with and without intellectual disability | X | | | | | UK | IV | | | X |
| 18 | Blacher, 2001 | Transition to adulthood: mental retardation, families, and culture | | | X | | | US | V | | X | |
| 19 | Dyke et al., 2007 | Down syndrome Needs Opinion Wishes study report | | | | X | | AUS | NA | | | X |
| 20 | Van Naarden Braun et al., 2009 | Activity limitations among young adults with developmental disabilities: a population-based follow-up study | X | | | | | US | IV | | | X |

(Continued)

Table II. (Continued).

| Ref. | Author, year | Title | Research article |  |  | Report | Book | Country | Level of evidence[a] | Topic |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  |  | Quantitative | Qualitative | Opinion |  |  |  |  | ICF | Transition | Intd Dis |
| 22 | Williams et al., 1997 | Effects of leisure education on self-determination, social interaction, and positive affect of young adults with mental retardation |  | X |  |  |  | UK | V |  |  | X |
| 23 | Cory et al., 2006 | Effects of a leisure education program on social knowledge and skills of youth with cognitive disabilities | X |  |  |  |  | US | IV |  |  | X |
| 24 | Devine et al., 2000 | Social acceptance and leisure life styles of people with disabilities |  |  | X |  |  | UK | V |  |  | X |
| 25 | Duvdevany et al., 2004 | Leisure activities, friendships, and quality of life of persons with intellectual disability: foster homes vs community residential settings | X |  |  |  |  | Israel | IV |  |  | X |
| 26 | Oates et al., 2009 | Leisure participation for school-aged children with Down syndrome | X |  |  |  |  | AUS | IV |  |  | X |
| 27 | McVilly et al., 2006 | "I get by with a little help from my friends": adults with intellectual disability discuss loneliness |  | X |  |  |  | AUS | IV |  |  | X |
| 28 | Hughes, 2001 | Transition to adulthood: supporting young adults to access social, employment, and civic pursuits |  |  | X |  |  | US | V |  | X |  |
| 29 | Ryan et al., 2000 | Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being |  |  | X |  |  | US | V |  |  |  |
| 30 | Van Cleve et al., 2006 | Part II: clinical practice guidelines for adolescents and young adults with Down syndrome: 12 to 21 years |  |  | X |  |  | US | V |  |  | X |
| 31 | Shaddock et al., 2000 | "Walking the talk" about self-determination |  |  |  |  | X | UK | NA |  |  | X |
| 32 | Laragy, 2004 | Self-determination within Australian school transition programmes for students with a disability |  |  | X |  |  | AUS | V |  | X |  |
| 33 | Halpern, 1999 | Transition: is it time for another re-bottling. 1999 annual OSEP project directors' meeting |  |  |  | X |  | US | NA |  | X |  |
| 34 | Halloran, 1993 | Transition services requirement: issues, implication, challenges |  |  |  |  | X | US | NA |  | X |  |
| 35 | Wehmen, 1993 | Transition from school to adult-hood for young people with disabilities: critical issues and policies |  |  |  |  | X | US | NA |  | X |  |
| 36 | Lachapelle et al., 2005 | The relationship between quality of life and self-determination: an international study |  | X |  |  |  | Canada | IV |  |  | X |
| 37 | Agran et al., 2000 | Promoting transition goals and self-determination through student self-directed learning: the self-determined learning model of instruction | X |  |  |  |  | US | IV |  | X | X |
| 38 | Wehmeyer et al., 1998 | The relationship between self-determination, quality of life, and life satisfaction for adults with mental retardation | X |  |  |  |  | US | IV |  |  | X |
| 39 | Wehmeyer et al., 2003 | The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning | X |  |  |  |  | US | IV |  |  | X |

(Continued)

Table II. (*Continued*).

| | | | Research article | | | | | | Level of | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Ref. | Author, year | Title | Quantitative | Qualitative | Opinion | Report | Book | Country | evidence* | ICF | Transition | Intd Dis |
| 41 | Stancliffe et al., 2000 | Substitute decision-making and personal control: implications for self-determination | X | | | | | US | IV | | | X |
| 42 | Grigal et al., 2003 | Self-determination for students with disabilities views of parents and teachers | X | | | | | US | IV | | | X |
| 43 | Wehmeyer et al., 1997 | Self-determination and positive adult outcomes: a follow-up study of youth with mental retardation or learning disabilities | X | | | | | US | IV | | | X |
| 44 | Wehmeyer et al., 2001 | Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments | X | | | | | US | IV | | X | |
| 45 | Gil, 2007 | Bridging the transition gap from high-school to college: preparing students with disabilities and their families | | | X | | | US | V | | X | |
| 46 | Duvdevany et al., 2002 | Self-determination and mental retardation: is there an association with living arrangement and lifestyle satisfaction | X | | | | | Israel | IV | | | X |
| 47 | Sandys, 2003 | Work and employment for people with developmental disabilities | | | | | X | Canada | NA | | | |
| 48 | Gosling et al., 2000 | An employment project as a route to social inclusion for people with learning difficulties | | | X | | | UK | V | | | X |
| 49 | Lemon et al., 2003 | Community based cooperative ventures for adults with intellectual disabilities | | | X | | | Canada | | | | X |
| 50 | Wehman et al., 1997 | Transition into supported employment for young adults with severe disabilities: current practices and future directions | | | X | | | US | V | | X | |
| 51 | Mank et al., 2003 | Supported employment outcomes across a decade is there evidence of improvement in the quality of implementation? | X | | | | | US | IV | | | |
| 52 | Mank, 1996 | Natural support in employment for people with disabilities: what do we know and when did we know it? | | | X | | | US | V | | | X |
| 53 | Hyde, 1998 | Sheltered and supported employment in the 1990's | X | X | | | | UK | IV | | | |
| 54 | Stephens et al., 2005 | A longitudinal study of employment and skill acquisition among individuals with developmental disabilities | X | | | | | US | IV | | | |
| 55 | Wistow et al., 2003 | Users views of supported employment and social inclusion: a qualitative study of 30 people in work | | X | | | | UK | IV | | | X |
| 56 | Jahoda et al., 2008 | Feelings about work: a review of the socio-emotional impact of supported employment on people with intellectual disabilities | | | X | | | UK | V | | | X |
| 57 | Banks et al., 2010 | Supported employment for people with intellectual disability: the effects of job breakdown on psychological well-being | | X | | | | UK | IV | | X | X |
| 58 | Roulstone et al., 2005 | Working futures: disabled people, policy and social inclusion | | | | | X | US | NA | | | |

(*Continued*)

Table II. *(Continued).*

| Ref. | Author, year | Title | Research article |  |  | Report | Book | Country | Level of evidence[a] | ICF | Topic |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  |  | Quantitative | Qualitative | Opinion |  |  |  |  |  | Transition | Intel Dis |
| 60 | Davies et al., 2009 | Transitions from school for young adults with intellectual disability: parental perspectives on 'life adjustment' | X | X |  |  |  | AUS | IV |  | X | X |
| 61 | Kraemer et al., 2001 | Transition for young adults with severe mental retardation: school preparation, parent expectations, and family involvement | X |  |  |  |  | US | IV |  | X | X |
| 62 | Brown et al., 2006 | The quest for ordinary lives: the integrated post-school vocational functioning of 50 workers with significant disabilities |  |  | X |  |  | US | V |  | X | X |
| 63 | Williams et al., 1997 | Effects of leisure education on self-determination, social interaction, and positive affect of young adults with mental retardation |  | X |  |  |  | US | IV |  |  | X |
| 64 | Hoge et al., 1995 | Recreation participation patterns of adults with and without mental retardation |  | X |  |  |  | US | IV |  |  | X |
| 65 | Dattilo et al., 1994 | Understanding leisure services for individuals with mental retardation |  |  | X |  |  | US | V |  |  | X |
| 66 | Mactavish et al., 2004 | Re-injecting spontaneity and balance in family life: parents' perspectives on recreation in families that include children with developmental disability | X | X |  |  |  | US | IV |  |  | X |
| 67 | Van Naarden Braun et al., 2006 | Factors associated with leisure activity among young adults with developmental disabilities |  | X |  |  |  | US | IV | X |  | X |
| 68 | Weiss et al., 2003 | Virtual reality provides leisure time opportunities for young adults with physical and intellectual disabilities |  | X |  |  |  | Israel | IV |  |  | X |
| 69 | Li et al., 2006 | Successful experience of people with Down syndrome |  | X |  |  |  | HK | IV |  |  | X |
| 70 | Buttimer et al., 2005 | Patterns of leisure participation among adolescents with a mild intellectual disability |  | X |  |  |  | UK | IV |  |  | X |
| 71 | Specht et al., 2002 | The importance of leisure in the lives of persons with congenital physical disabilities |  | X |  |  |  | Canada | IV |  |  | X |
| 72 | Harmon et al., 1998 | Transition from adolescence to early adulthood: adaptation and psychiatric status of women with 47,XXX |  | X |  |  |  | US | IV |  | X | X |
| 73 | Australian Institute of Health and Welfare, 2006 | Disability rates among Aboriginal and Torres Strait Islander people: updating the Indigenous factor in disability services performance indicator denominators |  |  |  | X |  | AUS | NA |  |  | X |
| 74 | Esbensen et al., 2007 | Factors predicting mortality in midlife adults with and without Down syndrome living with family | X |  |  |  |  | US | IV |  |  | X |
| 75 | Kobe et al., 1994 | Parenting stress and depression in children with mental retardation and developmental disabilities | X |  |  |  |  | US | IV |  |  | X |
| 76 | Ward et al., 2003 | Transition: the experiences of young people with learning disabilities and their families in England |  | X |  |  |  | UK | IV |  | X | X |
| 77 | Blackorby et al., 1996 | Longitudinal postschool outcomes of youth with disabilities: findings from the National Longitudinal Transition Study | X |  |  |  |  | US | IV |  | X | X |

*(Continued)*

Table II. *(Continued)*.

| | | | Research article | | | | | | | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Ref. | Author, year | Title | Quantitative | Qualitative | Opinion | Report | Book | Country | Level of evidence[a] | ICF | Transition | Intel Dis |
| 79 | Huber et al., 2010 | Personal perception and personal factors: incorporating health-related quality of life into the International Classification of Functioning, Disability and Health | | | X | | | Canada | V | X | | |
| 80 | Kober et al., 2005 | The effect of different types of employment on quality of life | X | X | | | | NZ | IV | | | X |
| 81 | Seltzer et al., 2001 | Quality of life of adults with mental retardation/ developmental disabilities who live with family | | | X | | | US | V | | | X |
| 82 | McIntyre et al., 2004 | Quality of life for young adults with severe intellectual disability: mothers' thoughts and reflections | | X | | | | US | IV | | X | X |
| 83 | Hanley-Maxwell et al., 1995 | The second shock: a qualitative study of parents perspectives and needs during their child's transition from school to adult life | | X | | | | US | IV | | X | X |
| 84 | Read, 2000 | Disability, the family and society: listening to mothers | | | | | X | US | NA | | | |
| 85 | Kohler et al., 2003 | Transition-focused education: foundations for the future | | | X | | | US | V | | X | |
| 86 | Knox et al., 2000 | Family control: the views of families who have a child with an intellectual disability | | | X | | | AUS | IV | | | X |
| 87 | Timmons et al., 2004 | Managing service delivery systems and the role of parents during their children's transitions | | X | | | | US | IV | | X | |
| 88 | Schneider et al., 2006 | Families challenged by and accommodating to the adolescent years | | X | | | | AUS | IV | | | X |
| 89 | Hendey et al., 2002 | Disability and transition to adulthood: achieving independent living | | X | | | X | UK | NA | | X | |
| 90 | Pownceby et al., 1997 | The Coming of Age Project: A study of the transition from pediatric to adult care and treatment adherence amongst young people with cystic fibrosis | | | | | X | UK | NA | | X | |
| 91 | Morris, 2002 | Moving into adulthood: young people moving into adulthood | | | | | X | UK | NA | | X | |
| 92 | Roizen, 2007 | Down syndrome. In: Batshaw ML, Pellegrino L, Roizen NJ, editors. Children with Disabilities | | | | | X | US | NA | | | X |
| 93 | Thomson et al., 1995 | The transition to adulthood for children with Down syndrome | | X | | | | UK | V | | X | X |
| 94 | Pascal et al., 2004 | Disability and transition to adulthood: the politics of parenting | | X | | | | UK | IV | | X | X |
| 95 | Mill et al., 2009 | Negotiating autonomy within the family: the experiences of young adults with intellectual disabilities | | X | | | | AUS | IV | | X | X |
| 96 | Carr, 1994 | Annotation: Long term outcome for people with Down's syndrome | | | X | | | UK | V | | X | X |
| 97 | Redmand, 1996 | Listening to parents: the aspirations, expectations and anxieties of parents about their teenager with learning disabilities | | | | | X | UK | NA | | | X |

*(Continued)*

Table II. *(Continued).*

| | | | Research article | | | | | | Level of | | Topic | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Ref | Author, year | Title | Quantitative | Qualitative | Opinion | Report | Book | Country | evidence$^a$ | ICF | Transition | Intel Dis |
| 99 | McConkey et al., 2002 | Parental perceptions of risks with older teenagers who have severe learning difficulties contrasted with the young people's views and experiences | | X | | | | UK | IV | | X | X |
| 100 | Gillan et al., 2010 | Transition from special education into postschool services for young adults with intellectual disability: Irish parents' experience | | X | | | | UK | IV | | X | X |
| 101 | Heslop et al., 2002 | Bridging the divide at transition: what happens for young people with learning difficulties and their families | | | | X | | UK | NA | | X | X |
| 102 | Cameron et al., 2002 | Enabling young people with a learning disability to make choices at a time of transition | X | | | | | UK | IV | | X | X |
| 103 | Tarleton et al., 2005 | Changes and choices: finding out what information young people with learning disabilities, their parents and supporters need at transition | | X | | | | UK | IV | | X | X |
| 104 | Mank et al., 1998 | Employment outcomes for people with severe disabilities: opportunities for improvement | X | | | | | US | IV | | | X |
| 105 | Betz, 2007 | Facilitating the transition of adolescents with developmental disabilities: nursing practice issues and care | | | X | | | US | V | | X | X |
| 106 | Morris, 1999 | 'Hurtling into a void': transition to adulthood for young people with complex health and support needs | | | | | X | UK | NA | | X | |
| 107 | US Department of Education, 2006 | Assistance to states for the education of children with disabilities and preschool grants for children with disabilities | | | | X | | US | NA | | | X |
| 108 | Keogh et al., 2004 | Children with developmental delays twenty years later: where are they? How are they? | X | X | | | | US | IV | | | X |
| 109 | Gallivan-Fenlon, 1994 | "Their senior year": family and service provider perspectives on the transition from school to adult life for young adults with disabilities | | X | | | | US | | | X | X |
| 110 | Murray, 2007 | Families' care work during the transition from school to post-school for children with severe disabilities | | X | | | | AUS | IV | | X | X |
| 111 | Burrows et al., 2001 | The post school outcomes of young adults with autism spectrum disorder | X | | | | | AUS | V | | X | X |
| 112 | Smart, 2004 | Transition planning and the needs of young people and their carers: the alumni project | X | X | | | | UK | IV | | X | X |
| 113 | Hudson, 2006 | Making and missing connections: learning disability services and the transition from adolescence to adulthood | | | X | | | UK | V | | X | X |
| 114 | Parmenter et al., 1991 | Transition education: a pilot program for students with disabilities in transition in the NSW Department of School Education | | | | X | | AUS | NA | | X | |
| 115 | Pilnick et al., 2011 | Just being selfish for my own sake..' balancing the views of young adults with intellectual disabilities and their carers in transition planning | | X | | | | UK | V | | X | X |

*(Continued)*

Table II. *(Continued).*

| | | | Research article | | | | | | | Topic | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Ref. | Author, year | Title | Quantitative | Qualitative | Opinion | Report | Book | Country | Level of evidence* | ICF | Transition | Intel Dis |
| 117 | Geyh et al., 2007 | Content comparison of health-related quality of life measures used in stroke based on the International Classification of Functioning, Disability and Health (ICF): a systematic review | | | X | | | Europe | IV | X | | |
| 118 | Sakzewski et al., 2007 | Clinometric properties of participation measures for 5- to 13-year-old children with cerebral palsy: a systematic review | | | X | | | AUS | | X | | X |
| 119 | Swanson et al., 2003 | Comparing disability survey questions in five countries: a study using the ICF to guide comparisons | | | X | | | US | V | X | | |
| 120 | Kennedy 2002 | In: Federal activities related to the World Health Organization's international classification of functioning, disability and health | | | | X | | US | NA | X | | |
| 121 | Madden et al., 2003 | The ICF as a framework for national data: the introduction of ICF into Australian data dictionaries | | | X | | | AUS | V | X | | |
| 122 | Mbogoni, 2003 | On the application of the ICIDH and ICF in developing countries: evidence from the United Nations Disability Statistics Database (DISTAT) | | | X | | | US | V | X | | |
| 123 | Arthanat et al., 2004 | The International Classification of Functioning, Disability and Health and its application to cognitive disorders | | | X | | | US | V | X | | X |
| 124 | Battaglia et al., 2004 | International Classification of Functioning, Disability and Health in a cohort of children with cognitive, motor, and complex disabilities | X | | | | | Europe | IV | X | | X |
| 125 | Rosenbaum et al., 2004 | The World Health Organization International Classification of Functioning, Disability and Health: a model to guide clinical thinking, practice, and research in the field of cerebral palsy | | | X | | | Canada | V | X | | X |
| 126 | Butcher et al., 2008 | Stuck in transition? Exploring the spaces of employment training for youth with intellectual disability | | X | | | | Canada | IV | | X | X |
| 127 | Beresford, 2004 | On the road to nowhere? Young disabled people and transition | | | X | | | UK | V | | X | X |
| 128 | King et al., 2007 | A framework of operating models for interdisciplinary research programs in clinical service organizations | | | X | | | UK | V | | X | |

*Level of evidence as adapted from National Health and Medical Research Council. In: NHMRC levels of evidence and grades for recommendations for developers of guidelines. 2009 Australian Government.
Intel Dis, Intellectual Disability; ICF, International Classification of Functioning, Disability and Health.

of a standardized normative group as measured by intelligence quotient (IQ) tests. The IQ range of scores for each category are; mild intellectual disability (50–55 to approximately 70), moderate intellectual disability (35–40 to 50–55), severe intellectual disability (20–25 to 35–40) and profound intellectual disability (IQ below 20 or 25).

Defining intellectual disability has been challenging, and further refinement and standardization is required [11]. The most recent revision to the definition, by the American Association of Intellectual and Developmental Disabilities (AAIDD), includes measure of IQ and adaptive behaviour, and levels of support needed to function in the community [12]. Recent research in the US with intellectually disabled young adults using the ICF framework emphasized the need to examine impairment by type and severity in order to adequately understand some of the complexities and differences in the acquisition of adult social roles among this group [13].

A population-based study in Western Australia indicated the prevalence of intellectual disability was 14.3/1000 livebirths, with 10.6/1000 for children with mild or moderate intellectual disability and 1.4/1000 with a severe level of intellectual disability [14]. Prevalence of intellectual disability was 1.6 times greater in males and 2.3 times greater in children of Aboriginal mothers [14]. In a cohort of 9,703 people in Western Australia, 35% had a biomedical cause for their intellectual disability, 5% were diagnosed with autism and for over 50% the cause was unknown [15]. Of the 35% with a biomedical diagnosis for their intellectual disability, the most common diagnosis was Down syndrome (15%) followed by genetic abnormalities and birth defects (12%), infections (4%) and other medical, chromosomal or toxic causes (4%) [15]. Common health issues in adolescents and young adults with intellectual disability are epilepsy, gastrointestinal problems, thyroid disease, obesity, and musculoskeletal problems related to spasticity and/or hypotonia. The prevalence of vision and hearing problems is also higher than in the general population [16]. In addition, individuals with intellectual disability have been reported to be up to seven times more likely to have a diagnosable psychiatric condition compared to those without an intellectual disability [17]. It has been suggested that youth with intellectual disabilities and co-morbid psychiatric disorders will confront additional barriers and their transition experience will be particularly difficult, specifically in tasks associated with housing, employment and social interactions [18]. These impairments of body functions and structures can have important impacts on a young adult's ability to participate in daily life and transition related activities including attending school or work.

## Activity and participation

### *Functional skills*

Within the activity domain the ICF describes a number of functional skills including self-care, communication, and domestic skills. As mentioned, the most recent definition of intellectual disability involves consideration of the individual's functional or adaptive skills as well as level of assistance required to complete activities of daily living [12]. Research surveying families of young people with Down syndrome in Western Australia ($n = 363$) found that young adults were most independent in their mobility and required the greatest assistance in communication, higher cognitive functions and more complex self care tasks [19]. Over 60% of those aged 18–25 years were able to understand everyday conversations and only about 60% were able to independently express their needs. Just over 40% could independently use the telephone and only 17% were able to use public transport independently.

Isolated impairment does not automatically result in activity limitations or restricted participation, although in severe intellectual disability and/or multiple impairments it does have a large impact across a range of domains [20]. These limitations then have direct impacts on these young people reaching transition outcomes such as employment. Limitations in activities and instrumental activities of daily living have been shown to be more prevalent in those with intellectual compared to other developmental disabilities [20]. Evidence from Australia has suggested that the best predictor of future capacity for work among young adults with a disability (40% of whom had an intellectual disability) was the student's ability to manage activities of daily living [21]. Behaviour had a weaker association with future capacity for work [21].

### *Interpersonal and social skills*

Within the activity and participation domain of the ICF, a range of interpersonal skills and social skills are described including elements of informal social relationships and family relationships. The impact of social skills training, independent living skills, and leisure activities included in transition programmes on post school outcomes has received little attention in the literature. It is known that young adults with intellectual disability commonly find it more difficult than those without an intellectual disability to form friendships, understand and develop sexual relationships, and access and engage meaningfully in their local community [22–24]. Research from Australia and Israel found that friendships appear to decline for adolescents once they leave the more formal supports of school, and it is primarily through employment and involvement in day activities that new social networks are formed [25–27]. For many, the immediate period post transition from school can be a very isolated and lonely time where most social contact is with immediate family or organised by the family [25]. Although transition support models have been developed and strategies suggested as to what is needed to implement these models to assist students with intellectual disability to achieve social, community, and civic-life outcomes [28], to date limited research has examined the impact of these on the young adult's wellbeing and participation in adult life.

### *Self-determination*

School education and the transition to vocational education/higher education or employment is described within the activity and participation domain of the ICF. An emerging concept in transition literature for young people with intellectual disability is the importance of self-determination. Self-determination theory describes an approach to human motivation and involves three essential needs; the need for competence, relatedness and autonomy [29,30]. Exploring the processes and conditions which foster the healthy development and effective functioning of individuals and enabling them to decide what is wanted, rather than have external providers "plan for" them are key, specifically in vulnerable populations such as people with intellectual disabilities [29,31,32].

Self-determination has been highlighted as a critical element in optimising outcomes in the process of transition from secondary school to adulthood for youths with intellectual disabilities, particularly in the United States [33–35]. Self-determination incorporates skills such as goal setting, decision making, problem solving, communication, self awareness, and self advocacy and has been found to have a significant link with quality of life [36,37]. Many have assumed that individuals with intellectual disability cannot become self-determined [38]; however, this has been disputed by researchers finding that self-determination status is impacted by environmental factors to an equal or greater extent than by personal characteristics [39–41]. People with intellectual disability therefore have the capacity to control their lives in a more meaningful way if supported to do so. Despite this, current research suggests that educators are, on the whole, unfamiliar with the construct of self determination and how to effectively foster this in youth with intellectual disability [39,42]. Transition planning and program development provide important opportunities to foster self-determination in students with disabilities [43]. While normalised, community-based environments have been reported to support and enhance self-determination, segregated environments such as congregated living and sheltered employment may limit opportunities for choice and decision-making, diminishing self-determination [44]. The value of teaching self-determination skills and behaviour has been described with thought that self-determination training should be a critical component of all transition-focused education programs [45].

A review of seven Australian transition programmes for young people with disabilities moving to adult life highlighted that the concept of self determination is increasingly influencing the structure and nature of transition programmes [32]. Others reported students who were more self-determined made significantly more advances in obtaining job benefits and earned more [40,43]. Overall, research has found that students who are more self-determined often have better outcomes across multiple life categories, including, employment, access to health and other benefits, financial independence and independent living [40,46]. Realisation of the importance of self-determination has resulted in policy changes and a greater focus on program development [46].

### Employment, post-secondary education and day options

The "Major Life Areas" chapter within the activity and participation domain of the ICF describes work and employment as well as vocational training and higher education [6]. Employment options for youth with intellectual disability are described as open employment, supported employment, and sheltered workshops. The latter are segregated work settings for individuals with a disability. Some report that sheltered workshops provide interesting work in which individuals take pride and receive training geared towards progression to open employment [47,48], whereas critics argue that workshops are exploitive due to low rates of pay, irrespective of disability subsidies [49]. The supports provided can be both formal supports and "natural supports," the support of other co-workers and supervisors in helping to learn and maintain new skills [50–52]. Issues with supported employment have been highlighted in some studies from the United Kingdom, which report low satisfaction due to poor relationships with co-workers and high employer demands for productivity [53]. Another longitudinal study investigating adaptive skills conducted in the United States, found that beneficial skills appear to be learned within integrative settings and lost within segregated work settings [54]. An important aspect of this research [54] was that although most participants were those with mild intellectual disability (~37%), there was adequate representation of all levels of intellectual impairment: moderate intellectual disability (~22%), severe intellectual disability (~16%), and profound intellectual disability (~20%).

Participation in supported employment has been reported to provide opportunities for independence and choice-making and has been associated with improved psychological well-being [55–57]. A systematic review of fifteen studies concluded that there were positive outcomes for people with intellectual disabilities entering employment specifically in terms of quality of life, well-being and autonomy. However, limitations of this research included the difficulties associated with accounting for other inputs into autonomy such as way of learning, experience, supports, self-knowledge and confidence, and the failure to account for variables within different workplaces [56]. Unemployment and being out of the workforce has been shown to negatively impact on an individual's self-esteem, confidence, work attitude and feelings of adequacy, resulting in a negative psychological attitude [58]. Families of children with Down syndrome in Western Australia reported that for those engaged in paid employment, one third were not satisfied with their options [19]. The key issues which were highlighted for this group included a limited number of hours available in open employment, together with long delays in being given the opportunity to try a particular placement [19]. A review of the issues and challenges associated with transition from school for youths with a disability focusing on the outcome of employment, highlighted that successful transition to employment is the responsibility of legislators and employers and educational authorities as well as the family of the person with the disability [59].

Individuals considered unable to engage in employment may participate in a range of "day services." Day services vary but they usually involve a range of activities that aim to promote skill development, recreation, and community inclusion. Australian parents of young adults with intellectual disabilities have reported a lack of adequate full day adult services and called for increased funding for services in this area [60] with this sentiment echoed in the United Kingdom [61,62].

### *Leisure*

Leisure participation is reflected within the activity and participation domain of the ICF under the "Community, Social and Civic Life" chapter. Leisure participation for adolescents with intellectual disabilities has been associated with emotional and psychological benefits and has been found, by researchers in the United States, to facilitate the development and generalisation of skills and adaptive behaviours across a variety of settings [63]. It is recognised that leisure activities for young adults with intellectual disability typically involve a few stereotypical activities. These activities often include arts and crafts and bowling, and usually occur in a segregated setting or in the community with other individuals with a disability [64,65]. Families in the United States have expressed concern in relation to the lack of opportunity for their children to engage in integrated recreation activities, with concern increasing as youth transition from their childhood family and educational support services [64,65]. Unlike typically developing youth, young people with intellectual disability do no adopt individualised patterns of recreation but appear to rely heavily on family recreation well into adulthood [66].

Participation in leisure activities has been reported as similar across all levels of intellectual disability, mild to severe. Research from the United States involving 490 young adults with disabilities suggested that high levels of engagement in leisure activities could be the result of parent run groups and recreational environments. These environments and networks are easily accessible and accepting of individuals with impairment. However, the researchers did not report on whether leisure activities occurred in segregated or integrated environments and they did not examine the role of choice in leisure activity participation [67]. A pilot study in Israel involving young people with cerebral palsy with severe intellectual disability investigated whether virtual reality systems can provide positive and enjoyable experiences and potentially lead to increased self-esteem and a sense of self-empowerment [68]. It was reported that the participants demonstrated a degree of enthusiasm during the virtual reality experience and some participants reacted to stimuli with appropriate goal-orientated responses [68]. The importance of participation in leisure activities has been highlighted by the finding from research in Hong Kong that limited participation in activities reduces opportunities for people with intellectual disabilities to realize they have control and choice over their lives [69]. Choice is an important part of the transition to adult life and contributes to quality of life for young people with intellectual disability. Research in Ireland revealed that access to and location of leisure activities were common barriers to participation for young people with intellectual disabilities [70]. Furthermore, fewer limitations in activities of daily living, educational attainment, and the acquisition of adult social roles were significant predictors of participation in leisure activities of youth with a range of developmental disabilities, including a proportion who had mild (19%) and severe (13%) intellectual disability [67]. In cohorts of people with physical disabilities, it has been found that greater involvement in leisure activities decreases stress, improves coping skills and adjustment to life [71]. However, there is a gap in knowledge in understanding this association among people with intellectual disabilities.

## Contextual factors

### *Personal factors*

Personal factors are the particular background of an individual's life and living and may include gender, age, race, social and cultural factors, accommodation and geographical location [6]. Minimal research has examined the relationship between transition outcomes and various demographic and socio-cultural characteristics among people with intellectual disability. In a United States study, males tended to have higher rates of employment than females, as did white Americans compared to African Americans, youth from metropolitan versus rural areas and those from higher socio-economic compared to lower socio-economic areas [72]. Indigenous Australians who have a disability have been reported to have poorer employment outcomes than non-Indigenous Australians with a disability. No specific research has investigated the transition process for Indigenous Australians or those from culturally and linguistically diverse backgrounds [73].

The majority of young adults with intellectual disability live with their family well into their adult years [19,25,44,74]. Ongoing demands of caring for a young adult with intellectual disability can place additional stresses on the family. Their need for alternative accommodation is increasing parallel to improvements in life expectancy [75]. Recent research conducted in the United Kingdom found that almost three quarters of young people with intellectual disability who had left school were still living at home [76]. Although most parents wanted housing options to be included in the transition planning process, this had only occurred in 10% of cases [76]. Where the young person had moved out of home, it was primarily as a result of parents' efforts and financial resources [76]. Other work in the United States has found that 4% of young people with intellectual disability were living independently upon leaving school and this proportion grew to 24% after five years post school transition [77].

### *Quality of life*

Measuring quality of life as a transition outcome for young people with intellectual disability is an emerging concept. Quality of life as a transition outcome captures not only conventional outcomes such as employment, but also subjective aspects such as personal well-being, autonomy and self determination [78]. The concept of quality of life has been integrated into the ICF as a personal factor, operationalising aspects of the personal perception domain [79].

Literature investigating quality of life in the United States and New Zealand, as reported by parents as a transition outcome for youths with moderate to severe intellectual disability, found that the young people who had left school had a better quality of life than those still at school [78,80]. Those in open employment were also more likely to have a better quality of life. It was suggested this may be due to parents associating leaving school with their child gaining greater independence and autonomy and non-school environments allowing for more choice making and autonomy. The study also identified adaptive behaviour as the strongest predictor of quality of life scores. Importantly, however, other family factors were also found to significantly impact on these areas of quality of life; family coping styles, parents' involvement in the transition process, parents' knowledge of adult services, and parents' satisfaction with the amount of help they received from services during the transition period [78]. Other research has highlighted the critical role families play in the well-being of individuals with intellectual disabilities during the transition period [81,82]. Thirty mothers of transition-aged young people with severe intellectual disability in the United States were interviewed regarding their son's or daughter's quality of life. The discussions, in nearly three-quarters of the interviews mentioned recreation, activities and hobbies as important components of their young adult's quality of life [82]. On the other hand, work (7%), communication abilities (10%) and health (13%) were rarely mentioned [82]. The relationship between the various domains of the ICF and quality of life is an area requiring further exploration to highlight which life areas are most impacted.

### *Environmental factors*

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors can either act as barriers or facilitators to an individual's functioning.

### *Families*

Families of young people with intellectual disability transitioning from school have compared this stressful and distinct phase of life to the time when their child was initially diagnosed [83]. Often the mismatch between the youth's physical size and adult maturation and their cognitive and functional abilities place families under increased pressure in relation to physically handling and managing behaviour which may be becoming more difficult to control and discipline [84]. However, family involvement continues to be considered an essential component of the transition process [85].

Transition tends to occur at a time when other important social changes are occurring within a family: the non-disabled siblings may be reaching young adulthood and leaving home; aging parents may mean the loss of an important source of informal support; and parents, more typically mothers, may find themselves in the dual caring role of supporting both their disabled young adult and aging parents. Grandparents and siblings of children and young people with Down syndrome have been reported as the two most common sources of informal support other than the spouse, highlighting the significant consequences of the family adjustments [19]. In addition, these changes are occurring when, for most families, there is a sudden decrease in formal supports when their disabled adolescent leaves school [86]. For some parents, this reduction in formal supports may mean they have to cease employment or reduce their working hours to care for their young adult as well as assume the role of trying to co-ordinate services received from a number of different agencies [87]. While this complex role of the parent emerges more from necessity rather than choice on the part of the parents, it can have the potential to limit the development of the individual's own self determination and choice making skills. These changes present both internal and external challenges to families trying to establish new routines that are compatible with a reasonable quality of life for all members, as reported in Australia [88]. Rather than the traditional measures used to measure the success of transition such as employment and independent living, it may be more pertinent to be considering using measures of family coping, well being and quality of life [88].

Parent involvement in transition planning is the most commonly cited predictor of a successful transition [89–92]. Individuals that appear to have the most success in achieving the transition are reported to have parents who are encouraging and supportive and have expectations that equate with achieving most aspects of adult life [93,94]. They are also likely to be prepared to advocate strongly on their young adult's behalf as well as fostering their independence. There is some evidence that supports the notion that parents who are able to provide this kind of support are relatively privileged in educational and economic terms and have the time, skills and money to fulfil the complex role required to support their young adult through the challenging and often prolonged transition period [94]. Research investigating autonomy of young people with mild intellectual disability within the family unit through interviews in Australia identified three approaches to reaching independence; defiant, passive, and proactive [95]. These authors presented the point that transition to adulthood for people with intellectual disabilities is not inevitably conflict-ridden. Young person involvement in service decision making and support from families to choose varied and valued roles and responsibilities within the family and community were shown to be important factors in reaching autonomy for these young people with mild intellectual disability [95].

Safety and risk have been described as a major concern for families during the transition period leading to parents being reported as over-protective [96]. This over-protectiveness may hinder an individual's development of social skills and choice making and can result in isolation and inactivity [97,98]. Although strategies to minimise this have been suggested (eg. "shared risk strategy") in reality few service providers are adopting this approach [99].

### Services

A key factor in the important transition from school to post-school is navigating the bureaucratic aspects. This aspect of transition is unique to people with disabilities and for people with intellectual disabilities usually involves shifting from segregated settings and extra supports, social services and formal supports in mainstream education [100]. Transition services have been reported to have difficulties providing families and young adults with information about future options and opportunities [101]. Key elements of how this should be done have been identified but reports suggest that this information does not appear to be adequately reaching its target audience [102,103]. Challenges accessing information will add barriers to a successful partnership between adolescents with intellectual disability and their families. Specifically it has been shown that young people with severe intellectual disability may have minimal or no involvement in transition planning processes [60]. A recurring theme amongst the limited evidence cited was the lack of options post-school [61]. Although it is generally thought that those with severe intellectual disability are unlikely to transition to any form of paid employment, they have been shown to be able to successfully participate in supported employment environments [5]. In a sample of 329 young adults, where 90% of participants had an intellectual disability, positive relationships with co-workers without a disability and work settings where co-workers had been trained in aspects of disability from supported employment personnel were key to this success [104].

Transitioning to adult health care services raises many issues for families and young people with an intellectual disability, including decreased access to coordinated services. Usually, the young people are transferred to a general practitioner who may lack the knowledge to deal with the complexities of their disability and hence may refer them onto a number of different specialists, ultimately resulting in fragmented and uncoordinated care. A review in transition for adolescents with developmental disabilities involving young people with mild to severe intellectual disability, suggests that empirically based service models are required to manage transition from paediatric to adult health care settings. This review also highlights that some of these service models are in early stages of development [105].

### Transport

Transport is cited within "services, systems and policy" within the environmental domain of the ICF. Lack of appropriate transport can have a significant impact on many activities including leisure, employment and making and sustaining friendships [26,106]. Transport options can be influenced by a number of factors. These include parental concerns about a young adult's safety both in terms of capability and vulnerability to strangers, geographical location particularly in rural areas, and paucity of resources to assist with transport training. A study of the experiences of 283 families and young people with intellectual disability transitioning from school in England found that only a third of young people who had left school had some level of transition planning which had transport options and/or training included in their plan [76].

### Policy and legislation

Legislation in the United States has led many of the changes related to transition for young people with a disability in the developed world. The Individuals with Disabilities Act (IDEA) Amendments of 1997 embody a coordinated set of activities and outcomes designed to adequately ensure the preparation of students with disabilities for all aspects of adult life. Central to this legislation is the development of an Individualised Education Program (IEP) for each student that is annually updated. The IEP is described in Section 614 of the IDEA Amendments and is a plan which is designed with the young person and family at age 14, outlining the needed transition services [107]. Regardless of these efforts, reports have described the transition process and post-school life in the United States as somewhat negative. Low levels of participation in the transition process and poorly coordinated planning as well as high levels of unemployment, restricted participation in community activities and a continued dependence upon families [108,109]. Similar issues have been identified in populations within Australia [110,111] and the United Kingdom [112].

In the United Kingdom, the publication in 2001 of the White Paper, Valuing People, was a mandate for agencies working with people with disabilities to work in partnership to achieve better outcomes for individuals with disabilities. In support of these policy changes, a number of service delivery initiatives related to transition have been developed in the United Kingdom. Regardless of these policy and legislation changes which identified some key underlying problems, transition remains difficult for young people with intellectual disability. The issues identified included the fact that transition was a low funding priority, planning is usually short term, there is organisational complexity, poor systemic coordination and a considerable gap between policy and implementation [113].

In Australia, legislation related to transition has not been formally developed in the way it has in the United States and the United Kingdom. However, the Commonwealth/State Disability Agreement in 1991 reflected a policy shift to enhance the rights of individuals with a disability. The legislation included access to support services to obtain a reasonable quality of life; the right to individualised educational and developmental opportunities, and the right to exercise maximum control over every aspect of their life [32]. In Australia, the recent "welfare to work" and "mutual obligations" policies are the source of much debate and indecision as to whether such initiatives will act as barriers or facilitators for individuals with intellectual disability. These initiatives, like others in the United Stetes and United Kingdom, have created uncertainty for some around income entitlements, health benefits and employment choices for individuals with a disability. Central to these initiatives has been the creation of "transition co-ordinator positions" considered to be critical to the success of the programs [114].

## Conclusion

The range of issues related to transition from school to adult life for individuals with intellectual disability are complex and multi-faceted. Over the past two decades, there have been many initiatives implemented within the developed world to try to facilitate a smooth and successful transition from secondary school, although very few have had positive outcomes in terms of fully participating in all areas of adult life. The ICF framework has allowed a structure by which some issues can be understood [6]. It allows the challenges and opportunities faced by young adults with intellectual disabilities leaving the school system to be viewed in a broader context than just the diagnosis and functioning levels of the individual. In particular, it allows consideration of the impact of environmental and personal factors that may influence an individual's ability to participate in life activities [39]. The use of the ICF provides a more integrative approach to gathering and sharing information with a universally understood language. Pilnick and colleagues (2011) highlighted that the mainstream psychological literature in intellectual disability has attempted to describe and account for conduct by people with intellectual disability according to individual characteristics rather than contextual influences [115]. Others have adopted the stance that intellectual disability is largely a social construct [116]. More recently, it has been argued that intellectually disability is more than a social construct [115]. The ICF provides a holistic framework to capture all of these domains. This framework has been used successfully not only as a framework for reviews [117], but also to evaluate outcome measures and their utility [118,119]. It has been used in governmental departments in developed and developing countries [120–122] and for classifications of particular disorders [123–125]. However, until now, the use of the ICF as a guiding framework has been omitted from the area of transition for young people with intellectual disabilities. In the context of this review, the ICF has highlighted the importance of environmental factors including family systems, post-school services and access to transport as specific areas for consideration during the transition from school to post-school for young people with intellectual disabilities. Policies, services, personal characteristics, and the family, the importance of which is being shown by emerging evidence, can be acting at this time as key facilitators or barriers to participation outcomes [85,88].

This review has highlighted significant gaps and weaknesses within the literature investigating transition from school to post-school for young people with intellectual disability. Research which involves the young people themselves is sparse and usually only involves those young people who have mild intellectual disability [126]. In addition, research has tended to focus on only one aspect of transition (e.g. employment or transition of health services) as opposed to taking a more holistic view of outcomes [127]. A recent review investigating the issues and challenges related to transition from school to post-school for youths with disability, used employment as their primary outcome. The authors briefly mention friendships and the role of work as being more than about income and productivity, yet they neglected to explore the value and importance of concepts of participation, and environmental and personal factors which impact the transition [59]. To our knowledge, there is no research from low and middle income countries (LAMIC) regarding transition from school to post-school for youth with intellectual disabilities. This reveals a gap in the literature which future research needs to address. Other limitations include the difficulty in viewing outcomes such as quality of life or autonomy as a closed system with single causal factors [56]. Failure to take into account workplace factors when investigating supported employment outcomes is another common limitation in transition literature for young people with intellectual disabilities [56].

The transition process has shown to be associated with substantial disruptions to family routines and responsibilities [60]. Family involvement continues to be considered an essential component of the transition process [85]. Their experiences provide information of strong practical value to improve services, highlighting the importance for service providers to understand family belief systems. This has been reported as imperative to developing an effective working relationship with families and therefore implementation of effective service delivery [88,128]. The overall picture indicates that policy and legislation adjustment as well as transition programmes and the development of resources has so far had little impact on improving the transition experience from school to post-school for young people with intellectual disabilities. It is imperative that future research acknowledges the challenges and issues with current research and amends research designs to close the gaps in the current knowledge base.

## Acknowledgements

The authors wish to acknowledge the helpful advice on the structure of the paper offered by Professor Gwynnyth Llewellyn, University of Sydney.

***Declaration of Interest***: We also gratefully acknowledge the Seed Funding from Australian Research Alliance for Children and Youth for the project "Leaving School: Maximizing participation and life outcomes in youth with an intellectual disability transitioning from secondary school to adult life" and the ongoing funding provided by the Australian Research Council.

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Appendix G: Journal article published in Child Indicators Research

Child Ind Res (2012) 5:375–391
DOI 10.1007/s12187-011-9134-2

# *To Feel Belonged*: The Voices of Children and Youth with Disabilities on the Meaning of Wellbeing

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Accepted: 26 December 2011 / Published online: 26 February 2012

**Abstract** The aim of this paper was to describe the meaning of wellbeing for children and youth with disabilities from their perspective. Twenty children and young people with a range of disabilities including, cerebral palsy, autism, Aspergers syndrome, Down syndrome, mild to moderate intellectual disability and vision impairment, participated in five focus groups and one interview. Groups were facilitated by at least two experienced professionals, including one scribe who recorded the discussions within the groups and took field notes on contextual information. Open coding was used to initially name and categorise data. Constant comparison methods were then used to compare codes and categories to advance the conceptual understanding. Six themes of the meaning of wellbeing emerged from the data describing participation, the importance of good friends, family factors, anxiety relating to performance at school, coping strategies/resilience, and personal growth and development. The concept of wellbeing from the child's perspective was described as feeling supported, included and respected, as well as feeling valued and capable. Ideas raised by children and young people have highlighted gaps within current indicator sets of children's wellbeing. These include reciprocal respect within relationships, coping

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strategies, feeling valued and having a positive sense of self. Children and young people can provide valuable input into research, regardless of impairment.

**Keywords** Participation · Quality of life · Disability · Focus groups

## 1 Introduction

It is estimated that people with disabilities make up 10% of the world's population (United Nations 2006a). In Australia, which has a broad definition of disability, the prevalence of people with disabilities is approximately 20%, and children with disabilities around 8.3% of those aged 0–14 years (Australian Institute of Health and Welfare 2008). In 1998, 144,100 Australian children aged 0–14 years (or 3.7% of the population of this age) were estimated to have a physical/diverse disability, either as a main disabling condition or an associated disabling condition (Australian Institute of Health and Welfare 2004). The next most common disability group among children was intellectual/learning disability (143,000 children or 3.7% of the population of this age), followed by sensory/speech disability (119,900 or 3.1%), psychiatric disability (43,600 or 1.1%) and disability related to acquired brain injury (12,700 or 0.3%). Evidence shows that children with disabilities often have poorer outcomes compared to their non-disabled peers in a number of areas including material wellbeing, health and safety, education, and emotional wellbeing (Australian Institute of Health and Welfare 2004; Richman 2008; Anderson et al. 2007; Williams et al. 2005; Decoufle and Autry 2002; Sullivan and Knutson 2000; Allen 2008; De et al. 2008; Emerson et al. 2008).

In 1990 the United Nations ratified the "Convention on the Rights of the Child" (CRC) thereby focusing on the responsibility of states to ensure children's safety and wellbeing (United Nations High Commissioner for Refugees 1989). While the Convention briefly touched on the special needs of children with disabilities it was only in 2006 that a specific convention on the Rights of Persons with Disabilities (CRPD) was adopted by the United Nations (United Nations High Commissioner for Refugees 2006). This Convention shifted the paradigm from viewing people with disabilities as recipients of medical treatment and in need of protection against discrimination, to individuals with their own rights capable of making decisions and being active members of society.

Following the ratification of the CRC a number of reports including the "State of the World's Children" (United Nations Children's Fund (UNICEF) 2011), "Child Poverty in Perspective" (United Nations Children's Fund (UNICEF) 2007) and in Australia "A Picture of Australia's Children" (Australian Institute of Health and Welfare 2009a) measured the progress of countries against specific indicators of children's health and wellbeing. Presence of disability has been used as a measure of poor outcomes for children. However, there has been little focus on wellbeing within this population. Currently, there is a lack of research on what indicators of health and wellbeing are appropriate to use for children with disabilities and there are very few studies that have asked children with disabilities what they view as important for their own wellbeing (Llewellyn and Leonard 2010; Huebner et al. 2002). This information is essential for the design and implementation of strategies to maintain and improve wellbeing in this population and also for the assessment of the success of these strategies.

While research exploring the views of wellbeing for children with disabilities is sparse, Rahi and colleagues (2011) found it possible to elicit children's and young people's hopes, aspirations and concerns through a child-centred method with young people with sensory impairments (Rahi et al. 2011). Research has been undertaken in variety of areas in the general population (Uprichard 2008; Fattore et al. 2009). The participants in these studies are typically developing children, without disabilities. If any have been diagnosed with disabilities, they are in a minority and not examined separately. One study investigating wellbeing from the child's perspective for typically developing children found that typically developing children viewed their wellbeing through the importance of relationships with others, the importance of agency and control in various aspects of life and the importance of safety and security (Fattore et al. 2009). The body of literature from the perspective of children and young people is gradually growing as children are acknowledged as 'social actors,' not only living within a structured childhood, but they themselves play a role in structuring their own childhood (Mason and Hood 2011). Research which describes the views and opinions of children with disabilities, a population who face many complex challenges, is sparse to non-existant, highlighting a large gap in current literature.

Children's wellbeing has been described in many different and often inconsistent ways (Pollard and Lee 2003). An American study comparing wellbeing measures for children with and without limitations stated that children's wellbeing was sometimes referred to as a 'child's environment' (Hogan et al. 2000). Wellbeing has also being defined as: an inherently positive state (happiness); the absence of wellbeing (depression); or in a collective manner (shared construct). Children's wellbeing has also been described as varying according to life phase, age, gender, ethnicity, ability and disability and by contextual factors, including socio-economic status and geographical location (Fattore et al. 2009; Frones 2007). The complexity of this phenomenon leads to difficulties in uniformly defining wellbeing and measuring wellbeing (Frones 2007). Defining wellbeing from the child's perspective therefore requires a broad approach to allow the child's true perspective to emerge and permit them to define wellbeing in their own terms, rather than imposing pre-conceived ideas on them.

A challenge associated with undertaking research in this area is that children's views will be dependent on a number of factors including type of disability, age and level of functioning (Hanafin and Brooks 2009; Australian Institute of Health and Welfare 2009b). The aim of this paper was to describe the meaning of wellbeing for children and youth with disabilities from their perspective.

## 2 Methodology

Focus groups were considered the most appropriate data collection strategy as the presence of peers helped to minimise participant stress and provide a forum for the participants to brainstorm together. They provide an efficient method of assisting the collection of rich data at low cost (Flick 1998). Conducting focus groups with groups of marginalised populations has been found to be particularly useful in previous research (Lorig 2001; Tietelman and Copolillo 2005).

## 2.1 Sample

A purposive sample (participants selected according to the needs of the study) was recruited from a variety of sources (Patton 1990). In order to gain a broader perspective, we recruited children with intellectual and physical disabilities. A number of disability service providers and schools were contacted to gauge interest in involvement in the study. The organisations and schools then made contact with families of potential participants and invited them to participate in the study. Families of the children were provided with an information sheet and were advised of the purpose of the study, what data would be collected and the use of research data upon completion of the study. Informed consent was obtained from the parents and guardians of the participants. Written consent from the children was gained in some cases; otherwise the children and youth provided verbal assent to participate. The research protocol was approved by the Human Research Ethics Committee of the University of Western Australia.

## 2.2 Data Collection

The groups were facilitated by three different experts who had training and experience with interviewing skills and working with children with disabilities. At least two facilitators were present at each group (including one scribe) and often a classroom teacher and/or education assistants. Where there was a classroom teacher and/or education assistants present, their contribution was minimal, to avoid influencing the young people's responses. The scribe recorded the discussions within the groups and also took field notes on environmental factors, non-verbal cues, whether teachers or education assistants were present in the groups, level of involvement of group members and group dynamics. A permissive environment which allowed the participants to feel safe and comfortable in volunteering their opinions and ideas was created (Krueger 1994). Two groups with children with autism spectrum disorder and/or intellectual disability took place in classrooms at the schools the young people were attending, one mainstream high school and one education support centre within a primary school. Two groups of young people with cerebral palsy were conducted at a disability support service and one group with young people with Down syndrome conducted at another disability support service. One interview with a young boy with vision impairment, took place in a quiet room within a mainstream high school. Each group met once.

It is important to ensure that research with children and young people involves simple, straightforward and easy to understand questions and foci (NSW Commission for Children and Young People 2005; Beresford 2004). Through a literature search and team discussions the term 'a good life' was agreed to be the most appropriate conceptualization of the concept of wellbeing for the participants (Ventegodt et al. 2003). The term 'happy life' was abandoned because it is emotionally focused and limited in scope. Happiness is a part of wellbeing, not necessarily the whole. Most other literature measuring wellbeing had pre-identified indicators of wellbeing (Australian Institute of Health and Welfare 2010). We did not take this approach because we wanted the children in this study to construct their own concept of wellbeing. 'A good life' is a general expression which is meaningful to the broader population, yet it is not an entity that exists in any given format or context (Frones 2007). It allows participants to define the term for themselves. This conceptualisation was used to avoid directing the discussions in any pre-conceived directions of the many ways wellbeing has previously been defined (Pollard and Lee 2003). Thus allowing the children to define the complex and multi-faceted concept in their own terms. The primary questions underpinning the focus groups were "What is important for a good life?" and "What are the barriers (or what gets in the way) of having a good life?" Data collection methods included group and one-on-one discussions, group brainstorming, drawing pictures with colourful felt pens and writing lists on large pieces of butcher's paper.

Conducting qualitative research with children with physical and intellectual disabilities is challenging with few examples in published research (Lloyd et al. 2006; Swain et al. 1998; Booth and Booth 1996). Within these focus groups and interview open questioning, rephrasing of questions and verbal and physical prompts were strategies used to encourage the participants to provide their responses and thoughts. In addition, participants were encouraged to write down and/or draw their thoughts and feelings concerning the topics raised. Although additional groups may have produced additional description of themes, five groups and one interview were sufficient to gain an in-depth description.

### 2.3 Data Analysis

The data provided by the five groups and one interview were analysed by a researcher who had not been involved in collecting the data. An open coding method was used to name and categorise the data (Strauss and Corbin 1990). Constant comparison methods were used throughout the coding and analysis of the data (Charmaz 2006). Codes were then categorised into broader categories that emerged to form the major themes (Cotty 1996). Credibility of the findings was further enhanced by a review of the coding by an expert in the field of qualitative research and another external researcher conducting a separate analysis using the same protocol (Mays and Pope 1995).

## 3 Findings

Six themes of the meaning of wellbeing emerged from the data describing participation. These themes include: the importance of good friends, family factors, anxiety relating to performance at school, coping strategies/resilience, and personal growth and development.

### 3.1 Participant Characteristics

Nine girls and eleven boys aged 8 to 16 years old with a range of disabilities participated in focus groups and one interview. Three children had Down syndrome, seven autism spectrum disorder/Aspergers syndrome, six cerebral palsy, one a vision impairment and three had an intellectual disability for which the cause was unknown. All of the participants attended either mainstream schools or education support centres within mainstream schools. The focus groups and interview lasted from one to three hours in length and took place in a variety of settings. Throughout the groups, all children were reported to contribute, however, due to the young people's varying level of functioning, some children's responses were more detailed than others. Pseudonyms are used to refer to the children in this paper.

### 3.2 Theme One: *"Having things to do"*

Participating in different activities was the most frequent topic of discussion in all focus groups. The children discussed participating in recreational activities, including dancing, bowling, volleyball, ballet, swimming, visiting the beach, attending concerts, playing sport, riding bikes, playing with friends, going to the movies, listening to music, listening to the radio and computer games; educational activities such as completing assignments, and homework; and social activities such as playing with friends, being in groups with friends, and spending time with friends.

Patterns in the data revealed that the children valued participation in personally meaningful activities. Mary a sixteen-year-old with Aspergers syndrome described why she enjoyed drama: *"Not so much sport, its not my thing. I do more drama… the thing I like about drama is getting to know people more, especially the comedy, that can be fun."* Nick, a fifteen-year-old boy with high functioning autism discussed how he felt about drawing *"I like just getting creative behind it, and expressing my feelings."* These comments highlight the importance that these children and youth place on participation in these activities. The idea of being in control of decisions surrounding participation also emerged in the discussions. Edward, an eleven-year-old boy with moderate intellectual disability described *"playing playstation two and getting more games—and getting to play them whenever you want."* Lincoln, a twelve-year-old with cerebral palsy also commented on how important being in control of an activity ensuring it is meaningful for him was: *"You have the right to do what you want and choose between things ... like choose where you want to go for a birthday party, what clothes you wear."*

The International Classification of Functioning, Disability and Health (ICF) describes participation as 'involvement in life situations' and does not discriminate between activity and participation in its coding. Harriet, a fifteen-year-old girl with Down syndrome reflected this 'involvement' when she said *"to feel belonged,"* not only referring to carrying out an activity but truly feeling a part of something. The original ICF (World Health Organisation 2001) drew attention to the importance of considering the activities and participation of adults with disabilities, and not merely body functions and structures. The Children and Youth version (World Health Organisation 2007) extended this perspective into the younger age ranges. The present study indicates that this emphasis on activities and participation is consistent with the world views of children with disabilities themselves. When questioned as to what makes a good life the children in this study did not talk about their bodily impairments and limitations, but of joining in with friends and family and having personally meaningful things to do. Research has demonstrated that participation doesn't necessarily depend upon level of impairment, and that children with similar levels of impairment experience diverse levels of participation and quality of life (Colver 2006).

The restricting influence that environmental factors can have on social participation may parallel the restricting influence that personal characteristics can have on participation for people with a disability (Fougeyrollas et al. 2002). In this study the impact of the environment on social participation emerged from the children's comments about the need to adapt activities to accommodate them or choose activities that would suit them. Ben, a ten-year-old with vision impairment discussed being involved in sport and playing music: "*You can't play many sports like you can't play cricket or tennis because the ball is too small for me with my vision, but they aren't the only sports out there…I can still play music I just need the notes enlarged. I play the piano.*" Attitudinal environment can also have an impact on participation, Ben commented on the negative impacts of social attitudes, "*people that just expect you to do things really. I mean most people are really great but there are some people who aren't… people who pretend there is nothing wrong with you and tell you to do this, and do that… people who think they are better than me because I have a sight problem.*" In response to the question 'what gets in the way of a good life' Emma a sixteen year-old-girl with Down syndrome said "*other people telling me things*" and Jackie a thirteen-year-old with cerebral palsy said "*people stopping you doing what you want—if they just say no or don't.*" The United Nations Convention of the Rights of Person with Disabilities states 'to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, transportation, information and communication' (United Nations 2006b). Research has highlighted that this is not always the reality for people with disabilities and that this is a goal towards which all countries must continue to work (Vik et al. 2007). However, the recognition of the importance of the environment in the interaction between human development and disability is a fundamental shift in paradigm which has the potential to positively impact on the participation of people with disabilities (Fougeyrollas et al. 2002).

### 3.3 Theme Two: *"The most important thing is good friends"*

The emphasis which young people and adults with disabilities place on friendships has been widely reported, although some young people with Down Syndrome may have few friends (Oates et al. 2009). The importance of friendships in a good life emerged from discussions within the focus groups. In response to the question: "What would be important for a good life?" Nick, a boy with autism spectrum disorder, responded, "*for starters, mine would be good friends.*" When asked about her favourite things to do, Harriet, a fifteen-year-old girl with Down syndrome, stated that "*the most important is good friends.*" Ben, a ten-year-old with vision impairment, discussed the value he placed on the quality of friendships, rather than the quantity: "*Having close friends rather than just lots of not close friends.*" Ben also explained how he would often spend his social time with adults when he was not able to participate in activities with his peers: "*Sometimes kids might be playing sports and I just go talk to the adults…they usually talk about restaurants and stuff…I've been to lots of restaurants as well so I can have an opinion about them.*"

Friends were described as providing a sense of belonging and acceptance, assistance with personal matters, support in decision-making and sources of information. They engaged in activities together and shared things with each other. Making friends and being included with friends were mentioned as an integral part of school life.

Friends who proved to be unkind (e.g., teasing them about their disability) or unreliable (e.g. betraying secrets *"My unfriendly Josh, I told him to keep this secret (and he didn't)"*) were cited as barriers to a good life. Research has identified that for young people with disabilities a central barrier to experiencing friendships is a lack of independence. This lack of independence has often been attributed to geographical, practical and safety issues (Cuckle and Wilson 2002). This highlights the impact that environmental factors can have on participation in friendships for young people with disabilities. However, environmental factors were mentioned minimally in this research. This could be attributed to the fact that the children and young people within these focus groups lived within close proximity of one another and in most cases attended the same school.

### 3.4 Theme Three: *"You know home is where the heart is"*

The influence of family factors on every child's wellbeing and health is well known, yet little research has examined this from the child's or young person's perspective, especially when the child or young person has a disability. Rachel, a sixteen-year-old with Down syndrome stated that *"it's hard at home."* Mary, a sixteen-year-old with Aspergers syndrome highlighted the positive aspects: *"I think you need to have a family to have a happy life yourself... sometimes they're not good families, but I'm drawing a nice family here."* Some of the children who came from families where their parents had separated discussed spending time with each parent individually. In response to 'what makes a good life?' Edward, an eleven-year-old boy with moderate intellectual disability, said *"spending time with Daddy... going to Daddy's house."* Harriet, a sixteen-year-old with Down syndrome, mentioned *"going shopping with mum."* Home was also described by some children as a safe place where they felt emotionally secure, Lincoln stated *"at home children are kind to you, they behave."*

The comments regarding families from the group discussions often made reference to siblings. Sibling relationships play a central role in development, modelling of behaviours and opportunities for play and social interactions (Noller 2005). Sibling relationships involving a child with a disability have been found to be similar to those of typically developing children and in some cases of children with Down syndrome a more positive relationship has been reported (Cuskelly and Gunn 2003). Participants in these groups described their siblings with respect. For example, Alistair, who has high functioning autism, commented in regard to his older sister *"she has a tendency to be very clever, and she helps me prepare for things. She's really modest too."* Daniel, another boy with high functioning autism who was present in the same group as Alistair had a twin sister *"I have a twin sister, she goes to high school. She really hates tomatoes, but likes tomato sauce."* Daniel went on to explain that he got to eat her tomatoes which was positive for him. Ben, a ten-year-old boy with vision impairment described the relationship he has with his brother: *"My brother helps me out, and when he has friends over I play with them, and when I have friends over [my brother] plays with them."* Frustrations and annoying experiences with siblings were also discussed in response to the question what 'gets in the way' of leading a good life. For example, Max, who had high functioning autism, described *"being annoyed by brothers and sisters."*

### 3.5 Theme Four: *"Nothing seems to stick in my brain"*

The young people with an intellectual disability in our groups expressed anxieties linked with underperforming academically. Children who did not have an intellectual disability also discussed their anxieties relating to performance at school. Little is known about the stress, worry and anxiety which may accompany these experiences and how they may impact on other areas of life such as behaviour, attention and self-worth (Buckley et al. 2006).

Alistair, a fourteen-year-old boy with high functioning autism commented about his experience of school *"I worry about getting everything done."* This comment was met with much consensus from the other six members of the group. Daniel, another fourteen-year-old boy with autism spectrum disorder added *"I wish we could do everything at school and then just go home."* Mary, a sixteen-year-old girl with Aspergers syndrome explained: *"I really don't like tests and exams. Especially because when there's lots going on at school, I generally focus on the test but nothing seems to stick in my brain."* Children with high functioning autism have also been found to experience higher levels of anxiety when compared both with children with specific language impairment and typically developing children (Gillot et al. 2001). These findings highlight the importance of managing this anxiety in a school context to ensure children and young people with high functioning autism are supported to attend to classroom activities and have adequate opportunities to learn.

Amber, an eleven-year-old with cerebral palsy explained her concern with repeating work *"having to do things again that you don't want to do, like homework if you rush it the first time and get it wrong."* In this same group, Lincoln who also had cerebral palsy mentioned *"not doing your homework (means) marks go down... get into trouble."* These particular participants, who did not have an intellectual disability, were able to identify the importance of school which, in turn, played a role in heightening their sense of anxiety. These children clearly understood the long term impact of not doing well at school, as Jackie said *"getting good marks at school so you can go to uni and have a good life, get a good job."*

Qualitative research involving typically developing children, which explored what constitutes wellbeing and what meaning children ascribe to it, identified three main themes: a positive sense of self, a sense of agency and feelings of security (Fattore et al. 2009). Fattore and colleagues (Fattore et al. 2009) concluded that children understood that rewards in the context of education were provided to those who did well, and that their feelings of self-worth were anchored in experiences of positive recognition, particularly in the educational context. The children and young people participating in the present study identified under-performance at school as an area which *'gets in the way of leading a good life.'* Children and young people with disabilities, specifically intellectual disabilities, perform more poorly at school in comparison with their non-disabled peers (Turner and Alborz 2003). This fact could contribute to the school environment acting as a barrier for young people with disabilities experiencing positive wellbeing. However, school has also been identified as the main source of opportunity for social interaction with typically developing peers and with peers with Down syndrome (Oates et al. 2009).

The children raised discussion pertaining to involvement within mainstream schools. For example, Ben, the 10-year-old boy with vision impairment spoke of being involved in sporting games with his typically developing peers, *"for cricket I use one of the bigger soft bouncy balls that are good for hitting... everyone there knows about (my vision impairment) and we just use the bigger ball and I don't think anyone minds."* Max a thirteen-year-boy with high functioning autism, who attended a mainstream school, mentioned how he learnt from his typically developing peers *"If you have friends, you can learn things about them... they might get you interested in other things."* Mirroring other children is a technique used by typically developing children during development to learn new skills and behaviours (Nielson 2006). Inclusive education provides this opportunity during everyday activities. Issues in segregated schooling include lower academic expectations, the fact that children with disabilities are removed from their communities everyday to attend school as well as social attitudes which did not allow children with disabilities into clubs and activities in their communities (Buckley et al. 2006). Inclusion of children with disabilities in mainstream schools needs to be carefully managed to ensure that it is not a negative experience for students and that there is positive acknowledgement and recognition of progress and achievement.

### 3.6 Theme Five: *"You need some way to cool down"*

A theme of resilience emerged throughout the data in the form of coping strategies and hardiness described in the face of bullying or negative experiences. The explanations were quite specific to the situations of the participants, yet an overarching theme of resilience was identifiable across the groups.

A few of the children recognised that their quality of life would depend on what they made of their life, not merely what happened to them. They appreciated that they had a responsibility to be active in managing their lives, developing life skills, striving towards their goals, and coping with problems. For example, Ben, the 10-year-old boy with vision impairment commented: *"A good life is basically like you can't be always sad about it, it's alright but just look on the brighter side"*

A recurrent theme of his interview was how to make the best of life. Ben was well aware of many things that he couldn't do (e.g., play cricket or tennis, drive a car, become a surgeon), but he repeatedly turned it into something positive *"I think about things I can be and can't be, my friends and I have a joke about if I was a doctor or a surgeon... You can have a laugh about it."* When he was prevented by his disability from doing one activity, he would find another or make it into a joke or reflect on how little it really mattered. He refused to let anything get him down, and his buoyancy and optimism were the secret of his view of a good life. He commented *"the Doctor said, if my sight doesn't get any better I can't drive a car but it's not the end of the world."*

Parallels between comments from the children and young people in these groups and those of typically developing children who were interviewed about their well-being were evident (Fattore et al. 2009). For example, a typically developing 14-year-old female, highlighted the importance of having time on her own to make her feel good. *"I think giving yourself time to think and process everything that is going on around you"* (pg. 64) (Fattore et al. 2009). Similarly, Sam, a twelve year-old-boy with cerebral palsy, explained how he dealt with his emotions and valued time alone for reflection *"its good to go to your room and just lie down on your bed and cool down if you're feeling really angry with someone or yourself."*

In Australia 26% of children in year 3 to 7 have been reported to be victimised by bullying every week (Slee and Rigby 1993). It has been reported that children with learning disabilities who have poor social skills and are excluded by their peers are more likely to become victims of bullying (Flynt and Morton 2004). The children in this research mentioned episodes of bullying that they had experienced. Lincoln, a twelve-year-old with cerebral palsy, commented, *"they want to make themselves feel good so they put other people down, they put you down all day and say mean stuff to you, make you feel left out."* Jackie, a thirteen-year-old with cerebral palsy, said *"[bullying] makes you feel small, you want to do the right thing but people are ganging up on you to do something you think is not right."* Bullying or peer victimization can have detrimental effects on an individual. It can lead to greater depression (Austin and Joseph 1996), lower self-esteem and self-worth (Andreou 2000; Piek et al. 2005), and the victims can experience lower levels of happiness (Rigby and Slee 1992). Service providers need to be aware of the prevalence of bullying amongst young people with disabilities and implement strategies to help these children identify and speak about bullying and teach them coping strategies to deal with negative social experiences.

### 3.7 Theme Six: "*Feeling good about yourself*"

Personal growth and development were discussed within some of the groups, including discussion of goal-setting, striving to do their best, not wanting others to underestimate them and facing their fears. Nick, a fifteen-year-old boy with high functioning autism, said *"I want to help others in their lives that are a bit less fortunate, give back to other people what they gave to me... not just about other people helping you."* The children and youth wanted to feel that that they were not merely passive recipients of disability services, but that they would have the skills to occupy a valued role in society.

Ultimately, quality of life is a subjective judgment. People have a good quality of life when they themselves judge it to be good and a poor quality of life when they themselves judge it to be poor. The children in this study acknowledged that their views of themselves were critical to their quality of life. Therefore, some children mentioned the importance of their own behaviour in having a good life. When they knew that they were behaving well, they felt good about themselves. Amber, an eleven-year-old girl with cerebral palsy, spoke about honesty *"[Being honest] makes you feel good inside that you've told the truth."* Similarly, Ella, a 10 year old with autism and mild intellectual disability discussed the importance of working hard, "*It makes you feel better when your working hard—having no pegs on your traffic lights.*" Peer pressure to behave in ways that the children and youth did not consider appropriate set up an uncomfortable cognitive dissonance for some, and they would rather resist the peer pressure than feel ashamed of themselves as Jackie explained *"When other people want you to do things that you think is not right... [it] makes you feel small.. you want to do the right thing but people are ganging up on you to do something you think is not right... [I] can tell the teacher, being honest."*

During a discussion with the facilitator about 'things that are important to leading a good life,' Harry, an eight-year-old boy with cerebral palsy, said *"the way you look,"* after further prompts about why, Harry explained *"because I don't care that I have tight muscles."* The issue of body image emerged again in a different group. Harriet, a fifteen-year-old girl with Down syndrome, explained the importance of *"feeling good about yourself and then when you look at yourself in the mirror you feel sad and upset and you want to do something about it."* These feelings and comments, regarding body image and physical attractiveness, mirror the feelings of typically developing adolescent females in the general population. Although, as young adults with Down syndrome have specifically identifiable facial features (Roizen and Patterson 2003), these anxious feelings about body image may be heightened within these young people. Perhaps education and awareness within the mainstream population regarding physical differences which people with disabilities experience could assist in minimizing these prejudices.

## 4 Discussion/Conclusion

The children and young people's comments about the factors that contributed to their wellbeing or detracted from it, revealed what was included in their own personal ideas of wellbeing. The above six themes can be further conceptualized into an overall picture of wellbeing from the young person's perspective. For the participants in this study, "wellbeing" included feelings of being supported, of being included and respected, of being viewed as valued and capable, and of having feelings of self-respect and self-esteem.

The value that these children and young people placed on their friends and family partly derived from their need to feel supported (they *"encourage you... can help you... support you when you make a decision"; "they bring peace to people")* and partly from their need to feel included and respected (*"you feel belonged"; "friends ... that... know that they like you and you like them"*), whereas their concern about bullies, was because *"they make you feel left out"*. Feeling valued and capable was also included in the concept of wellbeing. This was illustrated by the need to have *"something to go for, strive for"*, by a child's distress when people *"underestimate what I can do"* or *"think they're better than me"*, by a child's desire *"to help others in their lives that are a bit less fortunate, give back to other people what they gave to me... not just about other people helping you"*, and by a child's pleasure when he *"faced fears"* and *"did things I'd never done before"*. Self-respect and self-esteem were also included in wellbeing for these children, as shown by comments about *"feeling good about yourself"* (i.e. body image) and about your own behaviour (*"makes you feel good inside that you've told the truth"*).

Findings from these focus groups highlight the overall importance children and young people with disabilities place on participation. In describing participation, the children and youth went beyond simply doing the activity and they highlighted the need to 'feel belonged.' Feeling involved and taking a useful role in activities and situations was continually referred to within all of the groups across disability types. Confirming the meaningful role that 'being involved' has for children and youth with disabilities from the young person's perspectives goes a long way to validating the paradigm shift that is moving rehabilitation towards participation rather than focusing solely on impairment. As the United Nations stated over a decade ago 'enabling participation should now be one of the primary aims of rehabilitation services nationally and internationally' (United Nations 1994). However, a decade later, the question remains as to the extent that participation is enabled for people with disabilities. An issue with current research which attempts to measure participation is the strong focus on activity rather than on involvement, and the improvised nature of measurement of participation found within current research (Verdonschot et al. 2009). A review of current participation measures would be useful in clarifying the most useful validated measures to measure participation by children and young people with disabilities.

Within the discussions in the focus groups in this study, there was little conversation concerning medical conditions, hospital visits or doctors/therapy appointments. It seems, contrary to the current medical model employed by many services, that these factors contributed minimally to the children's and young people's views on wellbeing. The impact of environmental factors on participation and quality of life has recently being identified as a major barrier (Colver 2006; Colver et al. 2010). Societal and cultural contexts have also been found to have an impact on wellbeing (Bennett and Lu 2007). This study has highlighted some of those circumstances where environmental factors 'got in the way' of leading a good life (eg. the size of the ball during sporting games, attitudes and expectations of people around them). It is important to consider the specific experiences for each individual when reflecting on wellbeing. However, there is also great value in appraising wellbeing across children and young people with different impairments to gain a true reflection of the range of factors impacting on these young people's lives. The characteristics of the disabling condition, along with child and family factors and informal supports from the community, are all likely to have an impact on the outcomes for the young person (Patterson and Blum 1996). The creation of environments where children can optimally develop is a vital consideration (Patterson and Blum 1996). Service provision should give serious consideration to adjusting environmental characteristics and providing education to the wider community in order to have the most beneficial impact on the wellbeing of children and youth with disabilities.

A report entitled "*Child indicators of wellbeing and children with disabilities: mapping the terrains*" (available at http://www.aracy.org.au/publicationDocuments/Indicators_of_health_and_wellbeing_for_children_with_disabilities.pdf) highlighted the limited research examining how children and young people with disabilities experience and understand wellbeing (Llewellyn and Leonard 2010). The authors presented a comprehensive set of child indicators of wellbeing for children with disabilities developed from the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. Our research aimed to find out, from the perspective of children with a disability, what they see as important factors which contribute to, and act as barriers preventing their own wellbeing. Not surprisingly, many of the factors the children raised were reflected well within the set of wellbeing indicators developed from the UN Conventions. For example, the key themes of identity, parents and family, participation, dignity, education, development, environment and independence could be directly mapped to a number of the participant's comments. However, there were a number of ideas and factors raised by the children which were not reflected within the wellbeing indicators set developed in the above report. The present research highlights the importance of including children and young people in research and in the development of such indicator sets.

There were a number of topics drawn from this research that were not addressed within the wellbeing indicators set presented within the 'Mapping terrains' report (Llewellyn and Leonard 2010). We would suggest further research to refine these topics, in order to categorize and define them as indicators. Although, the results from this research may not be able to be generalized to the wider population of children and young people with disabilities, this research does highlight the fact that young people offer a different and important perspective. A number of topics which were identified within this research and were lacking within the indicator set are described. Children and young people were shown to value having the opportunity to receive respect and show respect, in the form of *'helping others'*. The reciprocal nature of these relationships was an element not previously addressed within the wellbeing indicator set. Importance of coping strategies and how these helped the children and young people lead 'good lives' was also discussed within this study although not apparent within the indicator set. Additionally, having the opportunity to feel valued and useful, body image and self-esteem were highlighted as factors influencing the children's and young people's wellbeing. These topics could be considered within an overarching theme of autonomy. Autonomy refers to being 'self-governing' and differs from independence as it goes beyond 'acting independently of adults and carers' (Llewellyn and Leonard 2010). Making decisions, having control over self and developing trust in the environment are all aspects which strengthen a young person's autonomous nature (Case-Smith 2005) and encompass the topics mentioned here; reciprocal respect within relationships, coping strategies, feeling valued and having a positive sense of self.

The 'Mapping terrains' report (Llewellyn and Leonard 2010) identified indicators related to family within the theme of 'identity' and 'parents and family'. However, there is no specific mention of the importance of sibling relationships. This study has highlighted the important role siblings play in child/youth wellbeing and should therefore be further explored in research as a potentially important indicator for child/youth wellbeing. As the report mentions, and as has been highlighted by many others, '*young people may pick up on areas of importance or consideration that adults may overlook or misunderstand due to differences in social and cultural contexts of children and adults* (pg 9)' (Llewellyn and Leonard 2010; NSW Commission for Children and Young People 2005; Hannafin and Brooks 2009). The discussions within these groups have drawn attention to gaps within the indicator sets from the perspective of the children and young people themselves.

Further research involving the views of children and youth with disabilities on developing indicators of wellbeing is required as this research was a small scale study investigating what indicators are important for children and youth with disabilities. This research gives an indication of areas which are important to consider when examining the wellbeing of children and young people with disabilities and what gaps there may be in indicator sets for typically developing children and young people and in the one instance of an indicator set developed specifically for children and youth with disabilities from the relevant UN Conventions. The importance of involving the children and young people in researching their own lives has been highlighted through this study and acknowledges the valuable contribution these young people can offer, regardless of impairment or disability. Further consultation is required to develop the best ways of translating the perspectives of these children and young people with disabilities into measureable indicators that can be reliably used to assess, overtime, progress being made toward ensuring the ongoing wellbeing of this group of young Australians.

**Acknowledgements** We wish to thank Jade Bogdanovs and Louise Ewing for conducting the focus groups and interviews. We gratefully acknowledge the participation of the children in this study, as well as the cooperation and assistance of their parents and the staff at the schools and disability service organizations. We would also like to acknowledge the ARACY Seed-funding Grant for making this project possible.

**Declaration of Interests** The authors report no declarations of interest.

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Appendix H: Journal article published in Child: Care, Health and Development

Child: care, health and development
Original Article
doi:10.1111/cch.12019

# Functioning and post-school transition outcomes for young people with Down syndrome

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Accepted for publication 16 September 2012

**Keywords**
adolescents, employment, ICF, intellectual disability

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## Abstract

*Aim* To investigate the relationship between functioning and post-school day occupation for young adults with Down syndrome.

*Methods* Families of young people with Down syndrome ($n$ = 269) aged 15–30 years in 2009 were recruited from the population-based Down syndrome 'Needs Opinion Wishes' database in Western Australia. Questionnaires were mailed to participating families and involved two parts, young person characteristics and family functioning; 203 were returned (75%). Of those families who returned questionnaires, 164 (80.8%) of their young adults had left school. Participation in post-school day occupations was the main outcome and included; open employment, training, sheltered employment or alternatives to employment (ATE).

*Results* Young adults were reported as participating in open employment ($n$ = 42), training ($n$ = 17), sheltered employment ($n$ = 64) or ATE ($n$ = 41) post-school. Those who reported better functioning in self-care, community and communication skills were more likely to be in open employment and/or attending Technical and Further Education compared with those attending sheltered employment and/or ATE after adjusting for age, gender and rural/metropolitan regions. Current health as measured by visits to a general practitioner (GP) and hospitalizations revealed a weak relationship with post-school day occupations, with increasing likelihood of participating in open employment or training with increasing hospitalizations and GP visits.

*Conclusions* Our analysis shows that functioning in activities of daily living was related to post-school day occupation. Current health status and behaviour were found to have a weak relationship with post-school day occupation adjusting for functioning in the final model.

## Introduction

Transitioning from school to post-school activities can be a stressful and worrying period, when young adults seek to develop their own identity and make decisions about their future (Bryant *et al.* 2010). For young people with intellectual disabilities, the challenges are intensified with additional barriers and complicated policies and services to navigate (Zigler *et al.* 2002; Forte *et al.* 2011). Young adults with Down syndrome, the most common genetic cause of intellectual disability, have a high prevalence of health conditions including cardiac, gastrointestinal, respiratory conditions, ear and eye disorders (Thomas *et al.* 2011). These health conditions can often influence both a young person's ability to function in activities of daily living (ADL) and quality of life (Meijboom *et al.* 1995; Halder *et al.* 2004; Hamann *et al.* 2007). For young people with Down syndrome transitioning from school, the extent to which functioning in ADL and participation in post-school day occupations is influenced by these health conditions is largely unknown.

The International Classification of Functioning, Disability and Health (ICF) is a framework used to classify health conditions, health-related states and health outcomes and has been used to guide research for people with disabilities (World Health Organization 2001). The value of the ICF in framing and guiding research in the area of intellectual disability is emerging in the literature (Jelsma 2009). The change of perspectives from the traditional biomedical model of disease to a more holistic biopsychosocial model calls for consideration of a number of contextual factors which can influence people's lives. The ICF provides such a framework and also helps to inform practical changes including service definition and eligibility (Kraus de Camargo 2011). For the purpose of this study, participation was defined as 'involvement in life situations' (World Health Organization 2001). While participation is discussed across a number of life areas, the main focus for this paper is participation in post-school day occupations.

A study of parents of young adults with intellectual disability living in the UK identified being well connected with other parents/professionals, being proactive within the process, having sufficient information and good-forward planning as central in achieving successful transition outcomes for their son/daughter (Heslop & Abbott 2007). An older Scottish study presented a disappointing picture post-school with young adults with Down syndrome participating in a narrow range of leisure activities with minimal placement in employment and continuing dependency on parents (Thomson *et al.* 1995). In Australia no clear outline exists of what constitutes good practice in relation to employment services post-school and no data are available on the long-term outcomes of people working in integrated settings (Parmenter 1999). Research in the USA has begun to investigate the role of self-determination in successful transition into adulthood for young people with intellectual disabilities (Wehmeyer & Garner 2003; Wehmeyer & Palmer 2003). However, the extent to which level of functioning in ADL impacts post-school outcomes remains to be investigated among young people with Down syndrome. We hypothesized that level of function in ADL would be related to post-school outcomes with those with better function in ADL being more likely to be participating in open employment. The factors identified in the literature may then impact on this relationship to varying extents.

Rigorous studies with large sample sizes and population-based data are sparse in the area of transition for young people with an intellectual disability (Foley *et al.* 2012). Little is known about the specific factors which are positively or adversely related to post-school outcomes. This research investigates the relationship between functioning in ADL and post-school day occupations for young adults with Down syndrome. Additionally, we aimed to identify those factors which may influence this relationship including the individual's physical and mental health, the type of school attended, the mother's emotional state and the level of involvement of both the young person and their parents in transition planning.

## Methods

This study is part of a nation-wide study of young adults with intellectual disability transitioning from school to post-school. In Western Australia (WA) young people with Down syndrome were identified through the population-based Down Syndrome 'Needs Opinions Wishes' study conducted in 2004 (Bourke *et al.* 2009). In 2009 questionnaires were distributed to those families whose children were aged between 15 and 30 years. These parent-report questionnaires consisted of two parts: part one collected information about the individual with Down syndrome including information on health, functioning and service needs, and specific transition-related issues, and part two collected information about the health and well-being of their family.

### Independent variables

As outlined in Fig. 1, elements of each domain of the ICF were measured using a range of valid and reliable outcome measures, and questions with categorical responses. Descriptions of measures included are shown in Table 1.

### Outcome

The participation domain of the ICF is described as 'involvement in a life situation'. Participation in day occupations was the main outcome and was categorized into either open employment, training, sheltered employment or alternatives to employment (ATE). Open employment refers to integrated employment by businesses in the community. Within open

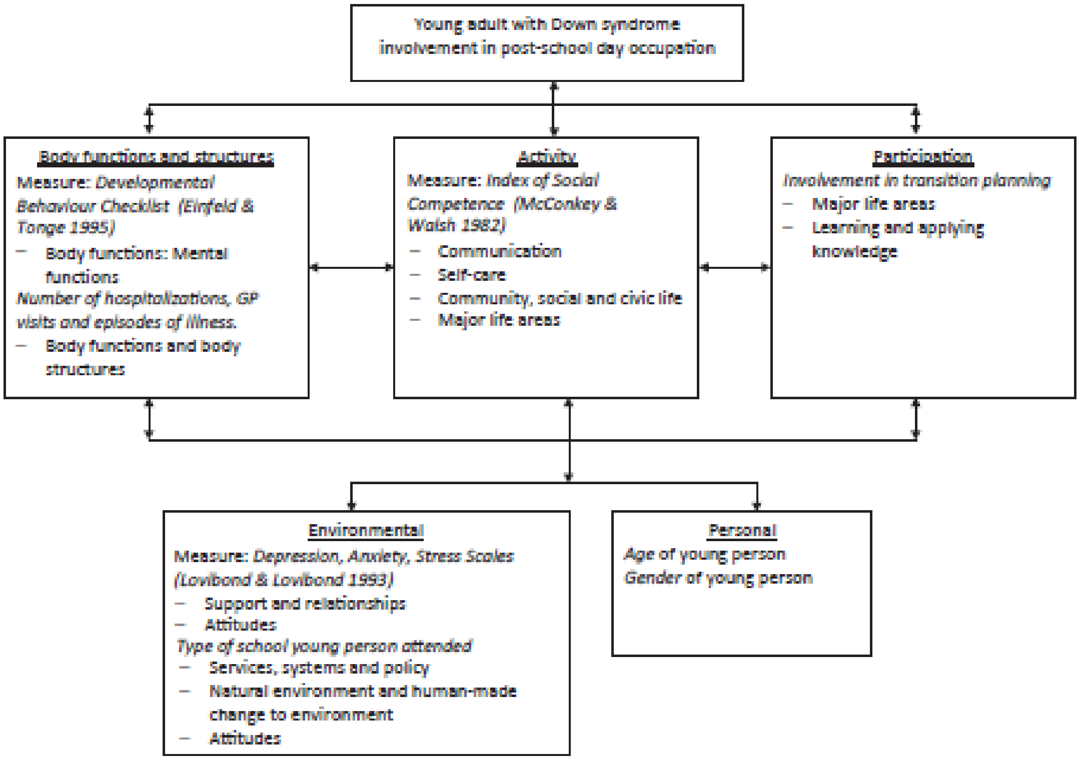

**Figure 1.** Methodology model as per ICF framework: second level classifications which are assessed within the ICF components. ICF, International Classification of Functioning, Disability and Health.

employment, some young adults may receive additional support (Wehman & Revell 1997). Training includes those attending a Technical and Further Education (TAFE) course or a post-secondary education programme. Sheltered employment settings are segregated work settings for individuals with a disability. In WA, ATE programmes are provided for those young adults who are not in either employment or training to support outcomes relating to social participation, increased independence, lifelong learning and enhanced support networks (Disability Services Commission 2009). A number of the young adults were reported as attending more than one of the above day activities. When this occurred, they were classified into the activity where they spent the most time or the activity which required the highest amount of skill, as defined in consultation with a community reference group of parents of young adults with Down syndrome (see Table 2).

## Data analysis

Analysis of variance and chi-squared tests were used to describe univariate relationships between the factors under investigation and the outcome, involvement in day occupations. Logistic regressions with binary outcomes were used in the final models allowing adjustment for confounders identified in the univariate analyses. These included: young person's age and sex, living region, number of siblings, family income and parent's age and occupation. Unadjusted and adjusted models were reported separately. STATA 11 was used for these analyses (Statacorp 2003).

Table 1. Description of measures and variables

| ICF domain | Construct measured | Measure | Direction of scores | Range |
|---|---|---|---|---|
| Activity | Functioning in ADL | Index of Social Competence (McConkey & Walsh 1982) | Higher score = better function | Sub-domains<br>Self-care skills: 0–26<br>Communication skills: 0–11<br>Community skills: 0–19 |
| Body functions and structures | Health state | Number of hospitalizations<br>Number of GP visits<br>Number of episodes of illness | Count | Count over the previous 12 months |
| | Behaviour | Developmental Behaviour Checklist (Einfeld & Tonge 1995) | Higher score = more behavioural problems | 0–192 |
| Environmental factors | Mothers emotional state | Depression, Anxiety, Stress Scales (Lovibond & Lovibond 1993) | Higher score = more emotional disturbances | 0–63 |
| | Type of school attended | Categorical | NA | Education support school/centre<br>Education support in government school<br>Education support in a private school<br>Mainstream |
| | Living region | Categorical | NA | Metropolitan<br>Rural |
| Participation | Involvement in day occupation | Categorical | NA | Open employment<br>Training<br>Sheltered employment<br>ATE |

ADL, activities of daily living; ATE, alternatives to employment; GP, general practitioner; ICF, International Classification of Functioning, Disability and Health.

Table 2. Description of combinations of day occupations within each group

| Post-school day occupation | *n* (%) |
|---|---|
| Open group | 42 (100) |
| Open only | 20 (47.6) |
| Open, TAFE and ATE | 12 (28.6) |
| Open and ATE | 4 (9.5) |
| Other combination | 6 (14.3) |
| Training group | 17 (100) |
| TAFE, sheltered and ATE | 8 (47.1) |
| TAFE and ATE | 9 (52.9) |
| Sheltered group | 64 (100) |
| Sheltered only | 49 (76.6) |
| Sheltered and ATE | 15 (23.4) |
| ATE group | 41 (100) |
| ATE only | 41 (100) |
| Total | 164 |

ATE, alternatives to employment; TAFE, Technical and Further Education.

## Results

Of the 269 questionnaires administered, 203 (75%) were returned. This study was restricted to the 164 young people with returned questionnaires who had left school. Their mean age was 22.9 years (range 15–29 years) and just over half (54.9%) were male. Almost all (90.2%) lived in the family home with the majority (78.0%) living in the metropolitan area. Nearly two-thirds (60.6%) were reported as having attended an education support unit in a mainstream school with the remainder attending an education support school/centre (30.3%) or attending a mainstream school (9.0%). Their mothers ranged in age from 37 to 80 years and fathers from 39 to 80 years. Compared with 55.7% of fathers, only one-third of mothers, lower than the 45% reported for the Australian female population (Australian Bureau of Statistics 2010a), worked in a job rated within the highest skill level based on the Australian and New Zealand Standard Classification of Occupations (ANZSCO). Annual family income classification was guided by the Australian Bureau of Statistics classifications (Australian Bureau of Statistics 2010b) and reported as less than AUS $33 799 by 25.2%, between $33 800 and $72 799 by 28.8% and $72 800 and above by 46.0%.

### Outcome

The most common main day occupation was participation in sheltered employment, attended by 39.0% of young people (Table 3). Fewer were working in open employment (25.6%) or only attending ATE (25.0%) with a minority (10.4%) attending training as their main day occupation.

### Activity

Those attending ATE scored consistently lower in community and communication skills, measured within the subscales of the

**Table 3** Univariate analysis of impairment, activity, person and environment factors as predictors of post-school day occupation

| | Post-school day occupation | | | | | Binary post-school day occupation variables | |
|---|---|---|---|---|---|---|---|
| | Total Freq (%) | Open employment (n = 42) Freq (%) | Training (n = 17) Freq (%) | Sheltered employment (n = 64) Freq (%) | ATE (n = 41) Freq (%) | Open employment and training (n = 59, 36.0%) Freq (%) | Sheltered employment and ATE (n = 105, 64.0%) Freq (%) |
| Person factors | | | | | | | |
| Gender | | | | | | | |
| Female | 74 (45.1) | 25 (59.5) | 8 (47.1) | 22 (34.4) | 19 (46.3) | 33 (55.9)* | 41 (39.1) |
| Male | 90 (54.9) | 17 (40.5) | 9 (52.9) | 42 (65.6) | 22 (53.7) | 26 (44.1) | 64 (60.9) |
| Age group | | | | | | | |
| 15–17 year olds | 9 (5.5) | 1 (2.4) | 2 (11.8) | 3 (4.7) | 3 (7.3) | 3 (5.1) | 6 (5.7) |
| 18–22 year olds | 66 (40.2) | 16 (38.1) | 8 (47.1) | 27 (42.2) | 15 (36.6) | 24 (40.7) | 42 (40.0) |
| 23–31 year olds | 89 (54.3) | 25 (59.5) | 7 (41.2) | 34 (53.1) | 23 (56.1) | 32 (54.2) | 57 (54.3) |
| Environmental factors | | | | | | | |
| Annual family income | | | | | | | |
| $72 800 and above | 51 (46.0) | 19 (57.6) | 5 (50.0) | 19 (44.2) | 8 (32.0) | 24 (55.8) | 27 (39.7) |
| Between $33 800 and $72 799 | 32 (28.8) | 8 (24.2) | 4 (40.0) | 12 (27.9) | 8 (32.0) | 12 (27.9) | 20 (29.4) |
| Less than $33 799 | 28 (25.2) | 6 (18.2) | 1 (10.0) | 12 (27.9) | 9 (36.0) | 7 (16.3) | 21 (30.9) |
| Place of residence | | | | | | | |
| Family home | 147 (90.2) | 38 (90.5) | 15 (88.2) | 57 (89.1) | 37 (92.5) | 53 (89.8)* | 94 (90.4) |
| Group home/hostel | 7 (4.3) | 0 | 0 | 4 (6.3) | 3 (7.5) | 0 | 7 (6.7) |
| Living alone | 5 (3.1) | 2 (4.8) | 1 (5.9) | 2 (3.1) | 0 | 3 (5.1) | 2 (1.9) |
| Living with family/friends | 4 (2.5) | 2 (4.8) | 1 (5.9) | 1 (1.6) | 0 | 3 (5.1) | 1 (0.1) |
| Living region | | | | | | | |
| Metropolitan WA | 124 (78.0) | 28 (70.0) | 11 (68.7) | 54 (85.7) | 31 (77.5) | 17 (30.4) | 18 (17.5) |
| Rural WA | 35 (22.0) | 12 (30.0) | 5 (31.3) | 9 (14.3) | 9 (22.5) | 39 (69.6) | 85 (82.5) |
| Type of school attended | | | | | | | |
| Mainstream | 14 (9.0)* | 6 (14.3) | 2 (12.5) | 3 (5.1) | 3 (7.9) | 8 (6.1)* | 6 (6.1) |
| Education support unit in mainstream school (Government) | 55 (35.5) | 18 (42.9) | 3 (18.8) | 23 (39.0) | 11 (29.0) | 21 (36.2) | 34 (35.1) |
| Education support unit in mainstream school (Private) | 39 (25.2) | 13 (31.0) | 9 (56.3) | 11 (18.6) | 6 (15.8) | 22 (37.9) | 17 (17.5) |
| Education support school/centre | 47 (30.3) | 5 (11.9) | 2 (12.5) | 22 (37.3) | 18 (47.4) | 8 (12.7) | 6 (6.1) |
| Parent demographics | | | | | | | |
| Mothers age | | | | | | | |
| 37–45 years old | 10 (6.1) | 1 (2.4) | 0 | 7 (10.9) | 2 (4.9) | 1 (1.7) | 9 (8.6) |
| 46–55 years old | 76 (46.3) | 21 (50.0) | 8 (47.1) | 31 (48.4) | 16 (39.0) | 29 (49.2) | 47 (44.8) |
| 56 years and older | 78 (47.6) | 20 (47.6) | 9 (53.0) | 26 (40.6) | 23 (56.1) | 29 (49.2) | 49 (46.7) |
| Fathers age | | | | | | | |
| 39–45 years old | 8 (5.5) | 0 | 0 | 4 (7.1) | 4 (11.8) | 0 | 8 (8.9) |
| 46–55 years | 58 (39.7) | 17 (41.5) | 6 (40.0) | 22 (39.3) | 13 (38.2) | 23 (41.2) | 35 (38.9) |
| 56–65 years | 59 (40.4) | 17 (41.5) | 9 (60.0) | 22 (39.3) | 11 (32.4) | 26 (46.4) | 33 (36.7) |
| 66 years and older | 21 (14.4) | 7 (17.1) | 0 | 8 (14.3) | 6 (17.7) | 7 (12.5) | 14 (15.6) |

**Table 3.** *Continued*

| | Post-school day occupation | | | | | Binary post-school day occupation variables | |
|---|---|---|---|---|---|---|---|
| | Total Freq (%) | Open employment (n = 42) Freq (%) | Training (n = 17) Freq (%) | Sheltered employment (n = 64) Freq (%) | ATE (n = 41) Freq (%) | Open employment and training (n = 59, 36.0%) Freq (%) | Sheltered employment and ATE (n = 105, 64.0%) Freq (%) |
| Mothers occupation | | | | | | | |
| 1 – Managers | 32 (33.0)* | 10 (38.5) | 3 (33.3) | 12 (27.3) | 7 (38.9) | 19 (30.7) | 13 (37.1) |
| 2 – Professionals/technicians/trades workers | 16 (16.5) | 6 (23.1) | 2 (22.2) | 2 (4.6) | 6 (33.3) | 8 (12.9) | 8 (22.9) |
| 3 – Community/Personal Service workers | 49 (50.5) | 10 (38.5) | 4 (44.4) | 30 (68.2) | 5 (27.8) | 35 (56.5) | 14 (40.0) |
| Father occupation | | | | | | | |
| 1 – Managers | 44 (55.7) | 18 (60.0) | 4 (66.7) | 13 (52.0) | 9 (50.0) | 22 (51.2) | 22 (61.1) |
| 2 – Professionals/technicians/trades workers | 14 (17.7) | 4 (13.3) | 1 (16.7) | 3 (12.0) | 6 (33.3) | 9 (20.9) | 5 (13.9) |
| 3 – Community/Personal Service workers | 21 (26.6) | 8 (26.7) | 1 (16.7) | 9 (36.0) | 3 (16.7) | 12 (27.9) | 9 (25.0) |
| Impairment factors | | | | | | | |
| Annual GP visits | | | | | | | |
| 0–1 | 29 (19.2) | 12 (30.8) | 2 (13.3) | 11 (18.6) | 4 (10.5) | 14 (25.9) | 15 (15.5) |
| 2 | 38 (25.2) | 9 (23.1) | 2 (13.3) | 20 (33.9) | 7 (18.4) | 11 (20.4) | 27 (27.8) |
| 3 | 22 (14.6) | 5 (12.8) | 5 (33.3) | 7 (11.9) | 5 (13.2) | 10 (18.5) | 12 (12.4) |
| 4 or more | 62 (41.1) | 13 (33.3) | 6 (40.0) | 21 (35.6) | 22 (57.9) | 19 (35.2) | 43 (44.3) |
| Episodes of illness | | | | | | | |
| 0–1 | 25 (21.6) | 10 (30.3) | 4 (28.6) | 4 (10.0) | 7 (24.1) | 14 (29.8) | 11 (15.9) |
| 2–3 | 50 (43.1) | 12 (36.4) | 6 (42.9) | 19 (47.5) | 13 (44.8) | 18 (38.3) | 32 (46.4) |
| 4 or more | 41 (35.3) | 11 (33.3) | 4 (28.6) | 17 (42.5) | 9 (31.0) | 15 (31.9) | 26 (37.7) |
| Hospital visits | | | | | | | |
| None | 133 (81.1) | 33 (78.6) | 14 (82.3) | 53 (82.8) | 33 (80.5) | 47 (79.7) | 86 (81.9) |
| 1 or more | 31 (18.9) | 9 (21.4) | 3 (17.7) | 11 (17.2) | 8 (19.5) | 12 (20.3) | 19 (18.1) |
| Activity | | | | | | | |
| Using a telephone | | | | | | | |
| Successful most of the time/all of the time | 44 (27.7)* | 23 (54.8) | 5 (31.3) | 10 (16.1) | 6 (15.4) | 28 (48.3)* | 16 (15.8) |
| Most of the time, with some assistance | 26 (16.4) | 8 (19.1) | 4 (25.0) | 9 (14.5) | 5 (12.8) | 12 (20.7) | 14 (13.9) |
| Some of the time | 40 (25.2) | 8 (19.1) | 6 (37.5) | 22 (35.5) | 4 (10.3) | 14 (24.1) | 26 (25.7) |
| Not at all | 49 (30.8) | 3 (7.1) | 1 (6.3) | 21 (33.9) | 24 (30.8) | 4 (6.9) | 45 (44.6) |
| Participation | | | | | | | |
| Young person involvement in transition planning | | | | | | | |
| Not at all | 32 (21.9)* | 1 (2.6) | 4 (26.7) | 11 (19.6) | 16 (44.4) | 5 (9.3)* | 27 (29.4) |
| A little/moderately | 62 (42.5) | 17 (43.6) | 6 (40.0) | 30 (53.6) | 9 (25.0) | 23 (42.6) | 39 (42.4) |
| Quite a bit/extremely | 52 (35.6) | 21 (53.9) | 5 (33.3) | 15 (26.8) | 11 (30.6) | 26 (48.2) | 26 (28.3) |
| Parent involvement in transition planning | | | | | | | |
| Not at all | 7 (4.6)* | 0 | 4 (26.7) | 3 (5.2) | 0 | 4 (7.1) | 3 (3.2) |
| A little/moderately | 35 (23.2) | 9 (22.0) | 2 (13.3) | 13 (22.4) | 11 (29.7) | 11 (19.6) | 24 (25.3) |
| Quite a bit/extremely | 109 (72.2) | 32 (78.1) | 9 (60.0) | 42 (72.4) | 26 (70.3) | 41 (73.2) | 68 (71.6) |

| | Post-school day occupation | | | | | | | | | | | | Binary postschool day occupation variables | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Open (n = 42, 25.6%) | | | Training (n = 17, 10.4%) | | | Sheltered (n = 64, 39.0%) | | | ATE (n = 41, 25.0%) | | | Open and training (n = 59, 36.0%) | | | Sheltered and ATE (n = 105, 64.0%) | | |
| Predictors | Freq | Mean (SD) | Min–Max | Freq | Mean (SD) | Min–Max | Freq | Mean (SD) | Min–Max | Freq | Mean (SD) | Min–Max | Freq | Mean (SD) | Min–Max | Freq | Mean (SD) | Min–Max |
| Impairment factors | | | | | | | | | | | | | | | | | | |
| Behaviour | | | | | | | | | | | | | | | | | | |
| DBC | *42 | 21.6 (17.2) | 2–73 | 16 | 23.1 (18.3) | 4–74 | 62 | 27.8 (21.1) | 2–64 | 41 | 38.0 (24.4) | 8–101 | 58* | 22.0 (17.3) | 2–74 | 103 | 31.8 (22.9) | 2–101 |
| Activity factors | | | | | | | | | | | | | | | | | | |
| Functioning (ISC) | | | | | | | | | | | | | | | | | | |
| Self-care | *42 | 22.3 (2.9) | 15–26 | 17 | 22.2 (2.9) | 16–26 | 64 | 20.2 (3.6) | 12–30 | 40 | 16.5 (5.3) | 7–26 | 59* | 22.3 (2.9) | 15–26 | 104 | 18.8 (4.7) | 7–30 |
| Community | *42 | 13.3 (3.7) | 3–18 | 16 | 12.3 (4.6) | 5–19 | 64 | 9.8 (3.8) | 3–18 | 39 | 8.4 (4.8) | 2–18 | 58* | 13.0 (4.0) | 3–19 | 103 | 9.3 (4.2) | 2–18 |
| Communication | *42 | 9.6 (1.3) | 6–11 | 17 | 9.4 (1.2) | 7–11 | 63 | 8.6 (1.4) | 7–11 | 40 | 7.7 (1.7) | 5–11 | 59* | 9.5 (1.2) | 6–11 | 103 | 8.22 (1.6) | 5–11 |
| Total score | *42 | 45.2 (6.7) | 27–55 | 16 | 43.8 (7.2) | 29–56 | 63 | 38.4 (7.5) | 26–53 | 39 | 32.9 (10.9) | 14–54 | 58* | 44.8 (6.8) | 27–56 | 102 | 36.3 (9.3) | 14–54 |
| Environmental factors | | | | | | | | | | | | | | | | | | |
| Parent emotional state | | | | | | | | | | | | | | | | | | |
| Depression | 40 | 17.5 (6.7) | 14–44 | 16 | 20.4 (9.5) | 14–52 | 58 | 21.0 (10.7) | 14–56 | 38 | 22.6 (10.1) | 14–54 | 56* | 18.3 (7.6) | 14–52 | 96 | 21.7 (10.4) | 14–56 |
| Anxiety | 40 | 16.9 (6.2) | 14–44 | 16 | 17.7 (6.3) | 14–39.2 | 58 | 19.62 (9.8) | 14–54 | 38 | 18.3 (5.0) | 14–32 | 56 | 17.1 (6.2) | 14–44 | 96 | 19.2 (8.2) | 14–54 |
| Stress | 40 | 19.8 (7.9) | 14–50 | 16 | 23.1 (9.3) | 14–50 | 58 | 23.8 (11.1) | 14–56 | 38 | 24.7 (7.7) | 14–44 | 56* | 20.7 (8.3) | 14–50 | 96 | 24.2 (9.8) | 14–56 |
| Total DASS score | 40 | 54.1 (19.7) | 42–132 | 16 | 61.3 (24.3) | 42–141.2 | 58 | 64.5 (30.3) | 42–166 | 38 | 65.7 (20.4) | 42–122 | 56* | 56.2 (21.2) | 42–141.2 | 96 | 64.9 (26.7) | 42–166 |

*<0.05. ATE, alternatives to employment; DASS, Depression Anxiety Stress Scales; DBC, Developmental Behaviour Checklist; GP, general practitioner; ISC, Index of Social Competence; WA, Western Australia.

**Table 4.** Activity, participation and contextual factors in relation to post-school day occupations: binary logistic regression of univariate and adjusted models

| | | **Outcomes** | | | | | |
|---|---|---|---|---|---|---|---|
| | | **Univariate models** | | | **Adjusted model** | | |
| | | **Day occupation (open and training vs. sheltered and ATE)** | | | **Day occupation (open and training vs. sheltered and ATE)** | | |
| **Predictors** | | **OR** | **95% CI** | ***P* values** | **OR** | **95% CI** | ***P* values** |
| Adjusted model includes all variables in one model | Functioning in ADL (total score)* | 1.13 | 1.08, 1.19 | <0.001* | 1.14 | 1.06, 1.22 | <0.001* |
| | Behaviour (DBC)* | 0.98 | 0.96, 0.99 | 0.007* | 0.99 | 0.97, 1.03 | 0.867 |
| | Episodes of illness* | 0.98 | 0.87, 1.12 | 0.813 | 1.02 | 0.87, 1.20 | 0.831 |
| | Mothers emotional state (DASS total)* | 0.98 | 0.97, 0.99 | 0.045* | 0.99 | 0.97, 1.02 | 0.935 |
| | Age | 1.03 | 0.94, 1.12 | 0.571 | 0.94 | 0.85, 1.10 | 0.582 |
| | Gender | 0.50 | 0.26, 0.96 | 0.038* | 0.82 | 0.33, 2.01 | 0.664 |
| Participation | | | | | | | |
| Young adult's involvement in transition planning | | | | | | | |
| Not at all | 32 (21.9) | Baseline | | | Baseline | | |
| A little/moderately | 62 (42.5) | 3.18 | 1.08, 9.42 | 0.036* | 1.84† | 0.38, 8.83 | 0.446 |
| Quite a bit/extremely | 52 (35.6) | 5.40 | 1.80, 16.19 | 0.003* | 3.87† | 0.73, 20.65 | 0.113 |

ADL, activities of daily living; ATE, alternatives to employment; DASS, Depression Anxiety Stress Scales; DBC, Developmental Behaviour Checklist.

*Odd ratios for continuous variables refers to a unit change.

†Adjusted for age, gender, living region, functioning, behaviour, number of siblings and family income.

Index of Social Competence, compared with those attending other day occupations (Table 3) (McConkey & Walsh 1982). There was no difference in reported self-care functioning scores among those in open employment (mean 22.31 SD 2.87), training (mean 22.24 SD 2.88) or sheltered employment (mean 20.20 SD 3.63). The final model showed that better levels of overall functioning in ADL increased the likelihood that the young adult would be in open employment and/or training when compared with those in sheltered employment or ATE (OR 1.14, 95% CI 1.06, 1.22) after adjusting for age, gender, behaviour, episodes of illness and mother's emotional state (Table 4). This odds ratio refers to a unit change in functioning score.

## Body functions and structures

Description of presence of impairments of body functions and structures, based on the annual number of hospitalizations, number of episodes of illness and number of general practitioner (GP) visits are shown in Table 3. Only 18.9% of young adults with Down syndrome were reported to have had one or more hospital visits in the previous 12 months. Of the 62 young adults who were reported as attending the GP four or more times in the previous year, 21 (33.9%) were attending sheltered employment and 22 (35.5%) attending ATE. Number of episodes of illness was included in the final model (Table 4) as considered the most appropriate of the health variables to represent impairment of body functions and structures. The influence of number episodes of illness in the final model was minimal (OR 1.02, 95% CI 0.87, 1.20).

There was a weak association between number of hospitalizations and number of episodes of illness with post-school day occupation (data not shown). Adjusting for confounding variables age, gender, living region, functioning, behaviour, number of siblings and family income the relationship became stronger with those participating in open employment and training more likely to report one or more hospitalizations (OR 4.39, 95% CI 0.83, 23.15) (data not shown in table).

The univariate relationship between poorer young adult behaviour, as measured by the Developmental Behaviour Checklist (Einfeld & Tonge 1995), and day occupation (Table 4) showed that young people with behavioural problems were less likely to be attending open employment and/or training compared with sheltered employment or ATE (OR 0.98, 95% CI 0.96, 0.99) yet in the final model when functioning in ADL was added to the model the relationship was no longer evident (OR 0.99, 95% CI 0.97, 1.03). The odds ratio refers to a unit change in DBC score.

## Environment

Parents of those young adults attending ATE had higher Depression Anxiety Stress Scales scores (Lovibond & Lovibond 1993) representing poorer parent emotional state (mean 65.65 SD

20.44) than those in open employment (mean 54.13 SD 19.73) (Table 3). In the final model, the influence of parent emotional state was attenuated (Table 4).

### Transition planning

Young adult and parent involvement in decision making during the transition process was rated as 'not at all', 'a little/moderately' or 'quite a bit/extremely'. Of the young adults ($n$ = 52) who were reported as being 'quite a bit/extremely' involved in decision making during transition, 40.4% were in open employment. Of the parents ($n$ = 109) who reported being 'quite a bit/extremely' involved, 29.4% of their young adults were attending open employment. In the final model (Table 4) young adults who were reported as being 'extremely' or 'quite a bit' involved in decision making during the transition process (compared with 'not at all') were more likely to be in open employment and/or training (OR 5.4, 95% CI 1.80, 16.19). However, this effect was reduced when confounding variables were included in the model (OR 3.87, 95% CI 0.73, 20.65) (see Table 4).

## Discussion

We found that the post-school day occupation of the young adult with Down syndrome was strongly related to their level of functioning in ADL. Not unexpectedly young adults who were reported as functioning better within self-care, community and communication skills were more likely to be participating in open employment or training than those in sheltered employment or ATE.

Those with better behaviour were more likely to be participating in open employment or ATE, but after adjusting for level of functioning in ADL this effect was reduced. Previous research has concluded that difficult behaviour can affect learning and social opportunities for young adults with Down syndrome (Buckley *et al.* 2006). Those able to behave in a socially acceptable manner were reported as more likely to have friends and be more successful at work (Buckley *et al.* 2006). Nevertheless we cannot take the direction of this relationship for granted. It is possible that the type of post-school outcome may have an influence on behaviour and not the reverse.

We had anticipated that poor health status would adversely impact workplace participation among young people with Down syndrome. We found only a weak relationship between number of episodes of illness and visits to GPs and post-school day occupation. In the univariate model more than four GP visits equated with less likelihood of being in open employment while we saw the reverse in the multivariate model. We also found that those who were reported to be attending hospital one or more times were more likely than those with no hospital admissions to be participating in open employment or training compared with participating in sheltered employment or ATE. This finding contradicted our initial hypothesis. However, investigation of reasons for hospitalizations revealed that those in open employment or training were attending hospital for more preventative and elective surgeries such as removal of wisdom teeth, removal of tonsils and circumcision. In contrast, the causal pattern for those attending sheltered employment or ATE was different and included conditions such as sleep apnoea, heart conditions, 'blocked kidney' or psychiatric assessment. Count of hospital visits did not prove to be a useful measure of health state for this population. We have previously shown that health appears to improve with age among this population (Thomas *et al.* 2010) and improvements in medical management over the past two generations have played a role in increasing the life expectancy for people with Down syndrome (Bittles *et al.* 2006; Thomas *et al.* 2010). We could therefore speculate that improvements in medical management may also have reduced the influence on young adult participation in day occupation.

Young adults' personal involvement in transition planning has been reported as an important element when transitioning from school to post-school and a factor which helps young people achieve their desired outcomes and is associated with positive outcomes such as better quality of life (Wehmeyer 1998; Halpern 1999; Laragy 2004). We found a strong relationship between young people's involvement in decision making during the transition process and their participation in open employment and/or training even after adjusting for age, gender, functioning in ADL and behaviour. This supports previous evidence (Laragy 2004) of the importance of young adult involvement in decision making during transition planning. Interestingly, after adjusting for family income and size this relationship reduced. This could be because of decreased availability of parental time to act as advocates for their son/daughter or decreased opportunities to access additional support because of financial constraints (Davies & Beamish 2009). A similar pattern was found in relation to the type of school the young person attended. That is, there was a strong relationship with a young person attending an education support unit in a private school and subsequent open employment and training. However, the inclusion of family income reduced the strength of this relationship, suggesting that family income and potentially other socio-economic variables also influence post-school day occupation. This finding is consistent with research with typically developing young people which found low socio-economic communities to be disadvantaged in terms of vocational transition (Marks 2006). Others have raised the issue that personal factors may contribute to motivation for participating in post-school education, regardless of disability status. These included preference for leisure, risk avoidance, lack of openness to new experiences and an aversion to an external locus of control (Fouarge *et al.* 2010; Polidano & Vu 2011). These were not explored in the current study and warrant further investigation.

The ICF provided a useful framework for this study to examine the relationships between different components of personal and family life and post-school day occupation. The ICF allowed the exploration of the association of elements of activity limitations, such as poor functioning in self-care, communication and community skills, with elements of participation, such as type of post-school day occupation attended. The clear relationship between limitations in the activity domain associated with varying participation highlights important dynamics within the ICF framework. We found less of a relationship between health factors, which we aligned with the body functions and structures domain, and participation than we did with activity and participation. The fact that the health of many young adults with Down syndrome has considerably improved suggests a decrease in additional burden on the health system (Geelhoed *et al.* 2011). We have also shown that at this stage in the life of young people with Down syndrome, health issues would not appear to be one of the major barriers to participation in optimal post-school day occupation.

The interaction of contextual factors, environmental and personal factors with the other domains of the ICF revealed complex relationships. The ICF acknowledges that each one of these entities has the potential to modify one or more of the others and that it is important to collect data on these constructs independently to explore associations and possible causal links between them (World Health Organization 2001). This is supported by the findings from the multivariate models through the influence of environmental factors such as family income and size. Environmental factors would appear to be having equivalent impact on young adult post-school day occupation as factors such as behaviour profile, which may be intrinsic to the persons themselves. Environmental factors such as availability of services, family involvement, social support and positive attitudes have been reported as critical for participation for people with intellectual disabilities (Verdonschot *et al.* 2009). Other authors have highlighted that different elements of the environment can act as facilitators and barriers at the one time (Noreau & Boschen 2010). This highlights the importance of conceptualizing the environment as a multidimensional rather than a one-dimensional construct (Noreau & Boschen 2010). Further research is needed to investigate the impact of specific environmental factors on community and workplace participation for young people with intellectual disability.

## Limitations

Difficulties measuring the individual domains of the ICF have been widely reported (Hammel *et al.* 2008; Verdonschot *et al.* 2009). We acknowledge that the measurement tools did not measure each domain in their entirety, yet they were the most appropriate measures for the population and provide accurate assessment of elements in each domain. Measuring the macro-levels of the ICF cannot be done easily, and the use of the second or third ICF classification levels may be needed to identify concepts precisely (Noreau & Boschen 2010). Specifically, the measure for impairments of body functions and structures underscored difficulties in interpreting results. The hierarchical classification of the main outcome, participation in post-school day occupations, was also a limitation of this research. This classification was developed following consultation with a consumer reference group and industry partners to ensure the best possible interpretation according to families' experiences and current policy and legislation in WA. The fact that the data for this study were collected at one point in time, limits our ability to make assumptions about variables predicting the range of post-school outcomes. This information provides valuable insight into relationships between variables, but additional research, including longitudinal studies are needed to identify predictors. Strengths of this research include the use of a population-based database and a high response fraction.

## Conclusion

This study highlights the relationship between functioning in ADL and post-school day occupations. We have shown that the relationship between poor behaviour and post-school day occupations is accounted for by level of functioning in ADL. This finding suggests changes are required in Western Australian transition processes which currently view poor behaviour irrespective of level of functioning as an indicator that a young adult should be directed towards ATE as a post-school day occupation (Disability Services Commission 2010). Contrary to the initial hypothesis, we did not identify a strong relationship between health issues and young adult's post-school day occupation, although limitations with the surrogate measure of impairment requires careful interpretation of this finding. Finally, the use of the ICF in this study has shown the value of the framework in guiding study designs in a complex issue, transition from school for young adults with Down syndrome.

### Key messages

- Young adults with Down syndrome who are higher functioning in activities of daily living are more likely to attend open employment or training rather than sheltered employment or other recreational day programmes.
- Young adults with better behaviour are more likely to participate in open employment or training; however, poor function in ADL reduces this likelihood.
- Health impairment does not affect post-school day occupations for young adults with Down syndrome.
- Environmental factors are just as important as health issues in regard to participation in post-school day occupations for young adults with Down syndrome.

## Financial support

Seed Funding from Australian Research Alliance for Children and Youth for the project 'Leaving School: Maximizing participation and life outcomes in youth with an intellectual disability transitioning from secondary school to adult life' (ARC grant number is: LP0989847).

## Financial disclosure

We certify that no party having a direct interest in the results of the research supporting this article has or will confer a benefit on us or on any organization with which we are associated AND, if applicable, we certify that all financial and material support for this research (e.g. NIH or NHS grants) and work are clearly identified in the title page of the manuscript.

## Acknowledgements

Ethical approval for the study was obtained from the Ethics Committee of the Women's and Children's Health Services in Western Australia. We thank the families for their participation and the Disability Services Commission of WA for facilitating the distribution of questionnaires. We also gratefully acknowledge the Seed Funding from Australian Research Alliance for Children and Youth for the project 'Leaving School: Maximizing participation and life outcomes in youth with an intellectual disability transitioning from secondary school to adult life' and the ongoing funding provided by the Australian Research Council. We would like to acknowledge Down syndrome WA and the contributing investigators on the grant: Carol Bower, Bruce Tonge, Vivienne Riches and Nicholas de Klerk.

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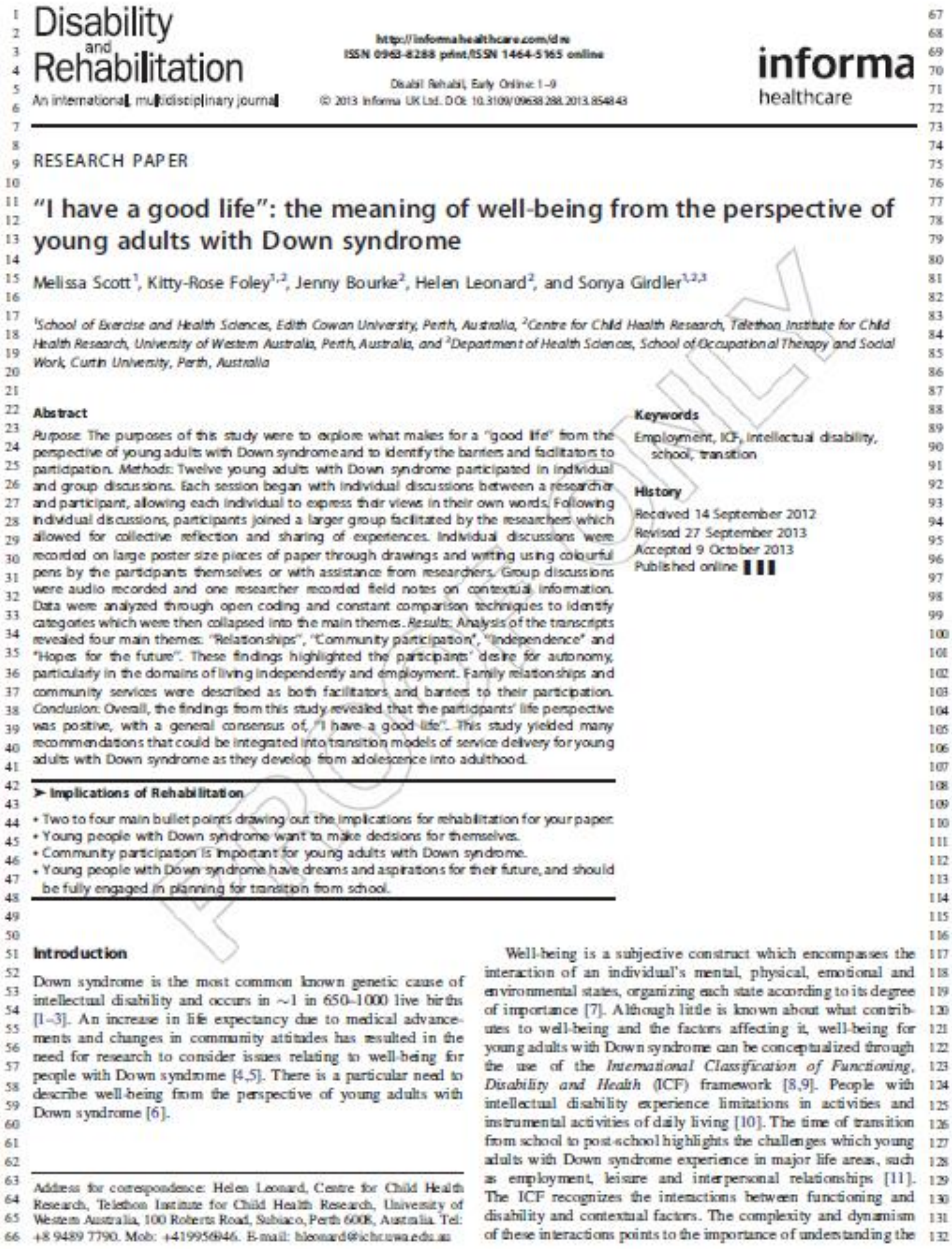
## Appendix I: Proofs of journal article published in Disability and Rehabilitation



Disability and Rehabilitation
An international, multidisciplinary journal

http://informahealthcare.com/dre
ISSN 0963-8288 print/ISSN 1464-5165 online

Disabil Rehabil, Early Online: 1–9

DOI: 10.3109/09638288.2013.854843

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RESEARCH PAPER

# "I have a good life": the meaning of well-being from the perspective of young adults with Down syndrome

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**Abstract**

*Purpose*: The purposes of this study were to explore what makes for a "good life" from the perspective of young adults with Down syndrome and to identify the barriers and facilitators to participation. *Methods*: Twelve young adults with Down syndrome participated in individual and group discussions. Each session began with individual discussions between a researcher and participant, allowing each individual to express their views in their own words. Following individual discussions, participants joined a larger group facilitated by the researchers which allowed for collective reflection and sharing of experiences. Individual discussions were recorded on large poster size pieces of paper through drawings and writing using colourful pens by the participants themselves or with assistance from researchers. Group discussions were audio recorded and one researcher recorded field notes on contextual information. Data were analyzed through open coding and constant comparison techniques to identify categories which were then collapsed into the main themes. *Results*: Analysis of the transcripts revealed four main themes: "Relationships", "Community participation", "Independence" and "Hopes for the future". These findings highlighted the participants' desire for autonomy, particularly in the domains of living independently and employment. Family relationships and community services were described as both facilitators and barriers to their participation. *Conclusion*: Overall, the findings from this study revealed that the participants' life perspective was positive, with a general consensus of, "I have a good life". This study yielded many recommendations that could be integrated into transition models of service delivery for young adults with Down syndrome as they develop from adolescence into adulthood.

**Keywords**

Employment, ICF, intellectual disability, school, transition

**History**

Received 14 September 2012
Revised 27 September 2013
Accepted 9 October 2013

**➤ Implications of Rehabilitation**

- Two to four main bullet points drawing out the implications for rehabilitation for your paper.
- Young people with Down syndrome want to make decisions for themselves.
- Community participation is important for young adults with Down syndrome.
- Young people with Down syndrome have dreams and aspirations for their future, and should be fully engaged in planning for transition from school.

## Introduction

Down syndrome is the most common known genetic cause of intellectual disability and occurs in ~1 in 650–1000 live births [1–3]. An increase in life expectancy due to medical advancements and changes in community attitudes has resulted in the need for research to consider issues relating to well-being for people with Down syndrome [4,5]. There is a particular need to describe well-being from the perspective of young adults with Down syndrome [6].

Well-being is a subjective construct which encompasses the interaction of an individual's mental, physical, emotional and environmental states, organizing each state according to its degree of importance [7]. Although little is known about what contributes to well-being and the factors affecting it, well-being for young adults with Down syndrome can be conceptualized through the use of the *International Classification of Functioning, Disability and Health* (ICF) framework [8,9]. People with intellectual disability experience limitations in activities and instrumental activities of daily living [10]. The time of transition from school to post-school highlights the challenges which young adults with Down syndrome experience in major life areas, such as employment, leisure and interpersonal relationships [11]. The ICF recognizes the interactions between functioning and disability and contextual factors. The complexity and dynamism of these interactions points to the importance of understanding the

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individual's own perspective of their well-being [8]. There are many environmental and personal factors that may influence well-being for young adults with Down syndrome [11]. Environmental factors such as negative community attitudes, influence the acceptance and involvement of young adults with Down syndrome into the community [12]. These attitudinal barriers impact on opportunities for employment, community living and consequently social interaction [13]. Young adults with Down syndrome are also often restricted in their community participation by parental attitudes and safety concerns, which may limit their decision making and transition to independence [13].

Contextual factors including parents' availability of time to arrange social meetings, parental mental health state and access to community supports impact friendships for young adults with Down syndrome [14]. Friendships may make the difference between integration into and isolation from the community for the young adults, and thus impact on well-being [15]. However, research suggests that opportunities for maintaining friendships and improving social interaction for young people with Down syndrome are often limited [14]. Maintenance of friendships is particularly difficult once these young adults transition from school to post-school as the opportunities for daily social interaction are reduced [14]. The importance of effective school transition programs is increasingly recognized in preparing and supporting young adults with intellectual disabilities into adulthood [16].

The impact of contextual factors on well-being for young adults with Down syndrome and the common practices of parents and carers serving as proxies in research have led to the need for research to describe the young adults' view regarding their well-being. If researchers are to avoid the essentially political act of furthering the stigmatization, disempowerment and marginalization of people with intellectual disability [17], they must work to overcome challenges, rather than assume inability of the individual to participate [18,19]. In addressing this need, the purpose of this study was to explore and define the meaning of well-being from the perspective of young adults with Down syndrome and to describe the facilitators and barriers to well-being. This understanding can then be used to inform and guide service delivery.

## Methods

Interviewing young adults with intellectual disability has rarely been attempted in research, due to the challenges presented in terms of limited communication abilities and difficulties with comprehension [20]. In this research, the inherent complexity of the concept of well-being posed significant challenges [21]. Consistent with a strategy adopted in previous research with children with intellectual and physical disabilities [22], the term "a good life" was chosen as the most appropriate conceptualization of well-being. The concept of "a good life" has currency within the general population, is broad, open to individual and group interpretation, without being pre-determined [21]. Therefore, the focus of discussions and interviewers in this research were to understand what makes a good life and what the facilitators and barriers were to a good life. As the collective experience of young adults with Down syndrome was the area of interest in this research a combination of focus group methodology and individual discussions was chosen as the most appropriate strategy [23]. Focus groups have particular utility when working with marginalized groups such as people with disabilities [24].

A purposive and convenience sample of 12 young adults with Down syndrome was recruited. Participants living a regional location in Western Australia were recruited from the Down syndrome Needs Opinion Wishes database [25]. Participants living in metropolitan Perth were recruited from an existing group run by the Western Australian Down syndrome parent association, Down Syndrome WA. Eligible participants met the following criteria: young adults with a clinical diagnosis of Down syndrome, between the ages of 18–30 years and living in the metropolitan or regional areas of Western Australia. Participants had to be able to speak comprehensibly or with only mild speaking difficulties.

An information letter briefly outlining the study and the time commitment involved was sent to parents of the participants prior to discussions. Before discussions commenced, the purpose and procedures involved in the research were explained to the participants by the researchers in plain language both verbally and in written format. Informed consent was obtained from the participants. The Edith Cowan Human Research Ethics Committee approved the research protocol.

### Data collection

Three group sessions each involving four participants ($n = 12$) were held, two were conducted with an established social group for young adults with Down syndrome at a community centre and one was held in a regional location. Groups were facilitated by four researchers with experience working with individuals with intellectual disabilities. Discussions were held at both the individual and group level. Each session began with individual discussions between a researcher and participant, allowing each participant to express their perspectives in their own words [26]. The individual discussions explored individual reflections on what made a good life, and personal and social matters. Following these discussions, participants met together as a group, which allowed for collective reflection and sharing of experiences [27]. Both individual and group discussions were directed by an interview guide (Appendix A). The interview guide consisted of eight open-ended questions, which were loosely followed throughout each session. The interview guide aimed to explore the young adults' ideas of what made them happy or sad, what helped or hindered their participation and, overall, what defined "a good life" for a young adult with Down syndrome. This guide was applied in a flexible manner with questions according to the participants' comprehension level, allowing for a variety of issues to be raised by participants [28,29]. Individual participants' responses and ideas were recorded on large, poster size pieces of paper using colourful pens by the participants themselves or with assistance from researchers. Group discussions were audio recorded. Although additional participants may have assisted in reaching saturation, three groups produced data which enabled description of emerging concepts, patterns and themes.

### Data analysis

All recorded discussions, both written and audio were integrated, transcribed verbatim and exported to Nvivo [30], which assisted with data management. The open coding method as described by Strauss and Corbin [31] was used to name, compare and categorize data. Significant statements were extracted from the raw data and were conceptualized and coded accordingly for further analysis [31]. Newly coded data were then grouped into broad categories and further analyzed in relation to similarities and differences in the data sets [31]. These were then organized into the major themes [26].

Purposive sampling was used to specifically select young adults with Down syndrome, who would be able to give expert comment regarding the purpose of the study [32]. Trustworthiness of the findings was achieved through multiple strategies. A review of the findings was undertaken by the executive of Down Syndrome WA to consolidate the findings to ensure credibility [32].

An expert in the field of qualitative research employed a further review of the coding to enhance the credibility of the findings. An audit trail recorded coding decisions, data analysis and the critical thinking process [33]. Reflective journals were also used to record ideas and assumptions in relation to the data, which were then checked by an expert colleague, to ensure it had not been influenced by personal biases [32].

## Findings

A total of 12 young adults with Down syndrome (six men and six women) participated in individual and group discussions. Participants' ages ranged from 18 to 29 years (mean = 21 years). The majority of participants were living at home with their parents ($n = 10$), one lived with a friend and one lived independently in close proximity to her parents' house. All but three participants experienced mild difficulty in speaking, with issues relating to their articulation. However, all participants' speech was appropriate and intelligible. Two group discussions lasted 45 min and one group discussion lasted almost 2 h. Within these times, individual discussions occurred and lasted from 10 to 20 min each. Data analysis revealed that for the participants in this study the meaning of well-being could be described according to four themes: relationships (including family, friends and intimate relationships), community participation (including education, employment, social and leisure activities), independence (autonomy, living independently and work opportunities) and hopes for the future (opportunity to drive, moving out of home, hope for a family).

## Theme one: relationships

Participants' discussions were dominated by the importance of having meaningful relationships in their lives with family, friends and intimate partners. These were described as "feeling loved", "spending time together" and "cuddles and kisses". Participants described meaningful relationships in the context of the workplace:

> It makes me happy being with friends and people at the community club (Andrew).
>
> Spending time with my family and my grandparents. I feel loved (John).

According to Erikson, the transition from adolescence to young adulthood is a very influential period in the young adult's life [34]. This stage is described as the process of identity formation versus role confusion, whereby the young adults are attempting to establish their sense of self in relation to their parents, friends and intimate partners [34]. For young adults with Down syndrome, it has been recognized that the reforming of these meaningful relationships during this stage is critical to their identity formation and well-being, and may often be seen as a period of confusion and stress [5].

### *Family relationships*

All participants relied on their parents to provide a secure environment where they felt loved, accepted and encouraged. Parents were also described as providing the young adults with opportunities to learn the skills needed to become independent. Overall participants described their relationships with their parents as positive and supportive. Jack, a 21-year-old young man described how his parents and carer helped him to negotiate the challenges of becoming an independent man:

> My parents have helped me practice to live by myself. Things like cooking and shopping. My Dad and carer give advice about relationships, manners with girls, talking about women, what they want, learning to be a gentleman.

Despite participants' need for parental guidance, their desire for autonomy and recognition as a young adult often led to conflict within the family. Participants felt that their parents and siblings were often too "controlling" and enforced "too many rules" upon them. Many of the young adults expressed that they felt "smothered" by their families:

> It's too hard for me to control my family. They boss me around like making me go to bed early, especially my sister. There are too many rules (John).
>
> I hate being told what to do (Jack).

Research has highlighted that parents of young adults with Down syndrome play an essential role in creating and moulding the identity of their adult children [13]. For young adults with Down syndrome, family relationships are central in shaping their attitudes and values, helping them to develop a clear idea of themselves as an adult [35]. Findings from the present study were similar to those of Docherty and Reid [13], who described parental attitudes of young adults with Down syndrome as maintaining values and expectations, which reinforced the "parent–child" relationship, and inhibited the young adults' independence into adulthood. Consistent with findings from this study, many parents continued to take an authoritative approach to parenting their young adults with Down syndrome, continuing to make decisions for them without discussion or consultation [13]. Craig [35] proposed that this authoritative approach to parenting may re-enforce child-like behaviours in young adults with intellectual disability. It was evident from the findings of this study that the participants were challenged in trying to reconcile both their need for support from their families and their desire for independence. Supporting families with a young adult with an intellectual disability to negotiate the transition from a parent–child to adult–parent relationship may help to families to cope with this tension.

### *Friendships*

Participants in this present study described friendship as highly valued and as making important contributions to their feelings of inclusion, acceptance and self-esteem. Friendships provided opportunities to participate in activities together, to "tell jokes", socialize and encouraged friendly rivalry between football teams. Participants were enthusiastic regarding their friendships:

> I like going out with friends to the pub and movies (Jack).
>
> On Friday evenings I go to the Café Club. I do some activities and games. Lauren and me we do dancing on Friday evenings . . . I do weights with my best friend. He is a really good friend (Andrew).

Friendships and social contacts are recognized as being particularly important for people with intellectual disability [36]. Friendships have been described as significant in establishing and developing self-identity through engaging and reminding each other of their "life stories" [37]. Such friendships are reinforced through meeting regularly, encouraging each other and participating in activities together [37].

Peer relationships are powerful especially during young adulthood and have the ability to foster both positive and negative social experiences [38]. Several participants in this study described occasions when they had been "bullied", "left out" or ‘‘teased’’. Participants described these experiences as ‘‘bad memories’’:

> At school there were bullies, they teased me. I got bullied at high school, I was embarrassed (Jane).
>
> I don't like it when friends leave me out, or other people out (Jack).
>
> I like nice people, but some people are nasty and tease me. I get sad when people at work tease me (Jane).

Many young adults with intellectual disability are bullied physically, verbally or emotionally, which often results in social withdrawal, loneliness and school drop-out [39]. These young adults who are bullied, lack the problem-solving skills necessary to take control over their situations and need to be taught how to solve problem, manage the stress of being bullied and develop coping strategies [40]. In this study, several participants described coping strategies which they had developed to help mediate the negative effects and the stress of being bullied [40]. Simon, aged 18 years, described his strategy for dealing with bullying at his workplace:

> I wear earplugs at work when people are bullying me so I can't hear what's going on (Simon).

While a considerable body of research has documented the important role of friendships for school-aged children with Down syndrome [14], only limited research has examined the role that friendships play for young adults. To date, this research suggests that young adults with Down syndrome experience problems in specific areas of socio-cognitive understanding [41]. The findings from our research suggest that young adults with Down syndrome experience some challenges with peer relationships, including experiencing bullying in their place of work. Future research should be directed not only at understanding the role of friendships for young adults with Down syndrome, but how they can be supported through interventions such as coping with bullying and social skills training.

### *Intimate relationships*

Participants described intimate relationships as having a ‘‘boy-friend’’ or a ‘‘girlfriend’’. Intimate relationships for participants were not typically characterized as physical and romantic, but were rather considered in part a status symbol of really being an adult.

Intimate relationships were expressed as an opportunity to have fun with a member of the opposite sex by ‘‘just hanging out together’’. Participants seemed to be more concerned with the desirable status of having a partner than companionship:

> I like spending time with my boyfriend. We have been together for one year. We met at the theatre. But I might find someone who is more handsome than my boyfriend and has better behaviour (Kate).
>
> I'm happy spending time with my boyfriend, just hanging out (Jane).

The attitudes of young adults with intellectual disability toward intimate relationships vary according to their level of disability [42]. Young adults with mild intellectual disability consider ‘‘dating’’ as an opportunity to have fun with a partner, whereby most interactions occur within a group setting [35]. The focus of an intimate relationship for these young adults has been described as physical attraction and the desire to raise awareness within the friendship group that they have a relationship status. Despite simple attitudes toward intimate relationships, many young adults with intellectual disability expressed the hope for marriage and a family, much like the general population [12]:

> I dream of getting married (Kate).
>
> I would like to be a mum and have children of my own (Julia).

Overall, findings from the present research indicate the important role that relationships play in ensuring a ‘‘good life’’ for young adults with Down syndrome. This finding is consistent with previous research which found a link between dissatisfaction with relationships and lower overall life satisfaction among people living with intellectual disability [43]. A powerful argument for the importance of relationships as a central construct in the concept of quality of life was recently made by Verdugo et al. [44]. As argued by Verdugo et al., the importance of relationships in underpinning quality of life points to the importance of models of service delivery such as person-centred planning in ensuring the human rights of people with intellectual disabilities.

## Theme two: community participation

Participants enthusiastically described their active participation in the community with the majority independently undertaking community activities including catching public transport and cycling in and around their neighbourhood. However, in activities where supervision or assistance was needed, participants relied on parents, siblings and carers for support and guidance. Participants engaged in a variety of community activities including; education, employment, social activities and leisure pursuits.

### *Education*

Continuing their education post high school was only considered important and practical for a few participants. These participants attended weekly classes at TAFE, the largest vocational education and training provider in Australia, to further their learning in practical skills such as cooking, typing and life skills:

> On Wednesdays I go to TAFE. I do maths and life skills. On Thursdays I do cooking (Andrew).
>
> At TAFE I do computer, typing skills and business. I like going to TAFE. My girlfriend goes to TAFE we do maths together (Jack).

Higher educational attainment has been associated with better employment outcomes for young adults with intellectual disability [45]. It may therefore be beneficial to encourage young adults with intellectual disability to pursue further education post-school to facilitate their acquisition of life skills and enhance their employment outcomes [46].

### *Employment*

Having a job was held in high regard by study participants who were engaged either in open or sheltered employment. Open employment included working in hospitality, fast food stores, department stores and waitressing.

> I work at Kentucky Fried Chicken. I look after the paper stock and boxes. I like it (Julia).
>
> I work waitressing, it's not too bad (Kate).
>
> I work at Kmart on Wednesdays, Thursdays and Fridays (John).

Participants who worked in sheltered workshops worked in the areas of woodwork manufacturing, gardening and cleaning services:

> I left school in year 11 and started working at [the sheltered workshop]. I learnt woodwork and can make pallets and chairs. I like going to work and looking after the machines (Kyle).
>
> I work doing gardening, cutting bushes and mowing lawn. I enjoy it (Simon).

Employment offers many benefits to all individuals, including a sense of purpose in life, income, social relationships and a structured daily routine [47]. Participation in employment can help young adults with intellectual disability to feel appreciated, important and included, employment can further contribute to an individual's identity [47,48]. Employment for young adults with intellectual disability positively influences mental well-being with those who are employed reporting higher levels of self-esteem, psychological well-being and lower levels of depression [49]. Clearly, employment is highly valued by young adults with intellectual disability and has a positive impact on well-being [49].

### *Social and leisure activities*

Similar to most young adults, participants in this study described their social activities as including, ''hanging out with friends'', attending social events such as football games and concerts, and participating in community groups. Many of their friendships and socializing occurred with other young adults with Down syndrome within their community social group:

> Going to the Miley Cyrus concert makes me happy (Julia).
>
> I like going out with friends, meeting them at the pub for beers. I like drinking heavy beers (John).
>
> On Mondays I go to the community centre for drama classes with some of my friends from one of my community clubs (Andrew).

Leisure is considered a voluntary activity, in which people engage through personal choice and preference with the main goal being to ''have fun'' [50]. Participants in this study engaged in leisure activities both individually and in groups. Leisure activities described included; sporting activities, listening to music and playing with pets:

> On Tuesdays I start my day by playing golf with my best friend. We hit a lot of balls, I'm good at golf, and I like it. Then we go to the gym (Andrew).
>
> I enjoy music, acting and dancing. Ballroom dancing is my favourite and I really want to perform on stage one day (Kate).
>
> I like listening to music by Jessica Mauboy, Cassie Donovan and the Bee Gees and Jazz music. My favourite band is the Bee Gees (Julia).

However, despite participants engaging in active leisure pursuits, many expressed their preference for more sedentary and solitary activities. Participants described these activities as including, watching T.V., reading and playing virtual games.

> I like playing Nintendo games and using the Wii wheel for active sport games (Justin).
>
> I like playing Wii games. I also enjoy watching T.V. My favourite T.V. shows are, Masterchef, Dancing with the Stars and Downton Abbey (Jane).
>
> I like cards, watching movies and playing games on my Playstation (Kyle).

Young adults with intellectual disability do not necessarily participate in leisure activities despite living within the community [50]. Many spend considerable time in solitary and sedentary activities which can lead to a loss of social skills and social isolation [12]. This is a major concern of parents, as many young adults with intellectual disability lack the knowledge and skills needed to take control over their own leisure participation and friendships [50,51]. However, research has also highlighted the importance of contextual factors including parents' availability of time to arrange social meetings, parental mental health, income status and access to community supports in influencing the leisure participation of young adults with Down syndrome [14].

Our findings revealed that participants in this study were actively involved in their communities, engaging in a variety of activities with opportunities to engage in and build relationships. Overall participants' experiences with leisure activities were described as positive. Despite participants often engaging in sedentary activities, many of them viewed this a time to ''relax'' from their other daily obligations. However, as participants in this present study were recruited from existing social groups it is likely that they represented a group, which had high levels of parental support and involvement. Our findings support those of Duvdevany and Arar [50] who reported that often young adults with intellectual disability required support from their parents to provide opportunities for leisure participation. However, these authors highlighted the importance of family support systems and an environment which encouraged freedom in leisure choices and social activities in supporting community participation.

For the young adults in this study being full and active members of their community was important to their wellbeing. This finding is consistent with the ICF [52] which has underscored the importance of participation in life areas as a fundamental right of people with disabilities. This research provides qualitative evidence that it is activity participation outcomes that are personally important to young adults with Down syndrome. This therefore suggests that any evaluation of the effectiveness of any interventions targeted at young adults with Down syndrome must assess their impact on outcomes relating to participation in life areas.

## Theme three: independence

Participants in this study valued "making [their] own decisions" and having the opportunity to choose activities, clothing or food that they enjoyed without the influence of their parents. They described their desire for freedom in their lives as wanting to live by their ''own rules'' independently, without ''nagging'' parents.

### *Autonomy*

Participants were collectively striving for autonomy in their lives. They described their desire to have control over their own lives, decrease their dependence on their family members and make their own decisions. Much like their non-disabled peers, many wanted to achieve autonomy in their decision making:

> A good life is being my own boss and living by my own rules (John).
>
> I want to be an adult, it makes me happy because that's how you grow up and learn to do your own chores (Lauren).
>
> I make my own decisions what I do. I'm wearing proper clothes and that's the best part. Looking nice is important (Kate).

The process of establishing a sense of self separate from parents is a major task in young adulthood [38]. Achieving autonomy is an important factor in achieving this sense of self [38]. However, despite parents of young adults with intellectual disability recognizing the need for autonomy in their child's life, many are aware that their young adults will always require ongoing assistance and support in their lives [13]. This tension often results in conflict in the parent–child relationship [13].

### *Living independently*

All of the participants in this study wanted to leave home and live independently. Participants viewed living independently as a chance to live without rules and parental control. Many wanted the same privilege as their siblings who had already left home.

> I live at home and I don't like. I would like my own place (Andrew).
>
> I dream of moving out of home it would be good. I'm an adult; it's a head start. I have three older sisters and they have all moved out (Kate).

Even though participants considered a ''good life'' to include living independently, only two participants had achieved this status and continued to rely on their parents and carers for support:

> I like living with my house mate (Kyle).
>
> I really like having my own place. I keep myself busy. On Mondays I've got a carer who takes me shopping (Jane).

Research has highlighted that parents of young adults with intellectual disability consider encouraging independence as important [53]. However, many parents feel that due to a lack of support and services they have little choice but to take control over the direction of their young adult's life [53]. As a result parents tend to limit their young adults' independence, becoming overprotective and often finding it difficult to gauge the level of independence of which their child is capable [53].

A suitable compromise for parents and young adults with intellectual disability may be ''supported'' or semi-independent living accommodation [54]. Semi-independent living involves one to four young adults with mild intellectual disability living together with regular part-time support from an accommodation support agency [54]. Semi-independent living for people with intellectual disability has been associated with improved quality of life, autonomy, social integration and personal choice [54].

### *Work opportunities*

Participants described that having the opportunity to work and to earn money was an important factor contributing to a ''good life''. They had mixed attitudes towards money. A few felt that saving their money for something more expensive, such as a holiday was more important than spending it on accessories, alcohol or sports betting:

> I like work and getting paid then I can save my money (Jack).
>
> I am saving my money for my holiday to Sydney (Kate).
>
> I like work. I like having money so that I can buy jewellery (Julia).

Although the majority of participants worked at least twice weekly, many expressed the desire to work more hours or work in a variety of environments. Due to their limited income, participants felt that they were restricted in their community involvement, with insufficient funds to support their social participation:

> Not having enough money stops me from doing the things that I want to do (Kyle).
>
> Not having enough money stops me from doing what I want to do like buying a house. I want to live independently like Jane [another participant] (Kate).

Participants described applying for new jobs, however, they felt that their choice of work was dependent on the opportunities that employers were willing to provide. Several participants described how at times their current jobs were preventing them from pursuing and achieving their life goals.

> I hope to get another job at a café serving customers but I'm waiting to hear back from the manager to see if he has hours for me (Jane).
>
> I'd like to be famous with cameras and make more money, but I'm stuck in a café (Kate).

Despite the benefits gained from employment for young adults with intellectual disability, equal employment opportunities are limited, with little to no increase in the number of people with intellectual disability participating in open employment in Australia over the last 10 years [55,56]. Even when employed young adults with intellectual disability are often hired for low-skilled, low-paid and casual positions [55]. Research has also highlighted that employer perceptions and attitudes play an important role in the success of employment for young adults with intellectual disability [55].

Like their typically developing peers, the young adults with Down syndrome involved in this study were striving for independence. Establishing the meaning of independence in the presence of a neurodevelopment disability such as Down syndrome poses many challenges for individuals, their families and service providers. Self-determination has emerged as an approach to service delivery which involves people with an intellectual disability in making their own decisions and determining their own futures, providing opportunities for them to engage with what independence means for them [57]. Self-determined behaviour for young adults with intellectual disability has been reported to promote choice making, self-control and self-advocacy in their daily lives [57]. Findings from this study highlight the importance of parents and carers encouraging their young adult with intellectual disability to be more self-determined, and controlling their own futures [57].

## Theme four: hopes for the future

According to Erikson [34] as adolescents move into young adulthood their search for their sense of self begins to fuse with their identity of who they are and who they hope to become. Overall participants' discussions were dominated by their future dreams, their hopes for a marriage, a family of their own, to live independently and most importantly to have the opportunity to drive.

### *Opportunity to drive*

Many of the participants described their desire to learn how to drive and own a car. Participants discussed their frustrations in having to depend on their parents and siblings to drive them. Many of the young adults felt that having their licence would give them the freedom to drive to the destinations of their choosing and it would, ''just make things easier'':

> If I got my licence if Mum was busy I could go out (Jane).
>
> I don't have a driver's license and that stops me from going to the places I want to go to. I want to get my license at some stage (Kate).
>
> If I could drive a car it would be easier. My sister can drive and she drives me. She is over 17 and she has just got her licence (Andrew).

Community mobility is essential for all people to engage in their valued occupations and positively impacts on employment, self-esteem, independence and quality of life [48,58,59]. Young adults with disabilities are faced with barriers which limit their mobility opportunities and result in dependence on family members for transportation [58]. The effect of not having a driver's license for young adults with Down syndrome often hinders their leisure and social activities and their attempts to become independent [58]. In the present study, it appeared that many of the parents of the young adults with Down syndrome had not yet addressed the difficult topic of their young adults possibly never being able to drive. Given these findings it may be beneficial for parents and community services to address this issue through encouraging the independent use of public transport.

### *Marriage and a family*

Participants frequently expressed their desire for marriage and starting a family. In particular, a few of the young women in this study discussed the prospect of becoming a mother and raising children. In this study, many of the participants were already couples and openly discussed that at some point in the future, marriage, children and a life together was the next inevitable step in their relationship. Lauren, a 23-year-old woman described her plans to become a mother:

> I want to become a mother some day and have children, two boys and two girls.

Kate's partner in the group commented:

> Hey, I can be the Daddy; I want to keep you happy (John).

Many of the participants described similar plans for their future with their partners:

> I dream of moving out and getting married. I'd like to be a married woman; I've got a boyfriend. My sisters have children. I wish I could have children (Kate).
>
> I like spending time with women. I would like to get married some day (Jack).

In this study, the young adults expressed their desire for intimate relationships, marriage and parenthood. The issues relating to intimate relationships of young people with intellectual disability are often challenging for parents [60]. Parents of young adults with intellectual disability tend to have a conservative view of marriage and the sexuality of their young adults [60]. Parents are often reluctant to address these difficult issues, despite increasing positive community attitudes towards sexual expression and marriage for people with intellectual disability [42].

Due to conservative parental attitudes, many young adults with intellectual disability have a low level of knowledge regarding safe sex practices, contraception, sexually transmitted diseases and the difference between sexual consent and abuse [42]. There is a need for young adults with intellectual disability to receive sex education both for their protection and knowledge [42].

### *Moving out of home*

As previously described, participants' discussions were dominated by the desire to live independently. However, despite most participants not yet having achieved independent living, the aspiration to ''move out of home'' and own a house was consistently described as a symbol of becoming an adult:

> I want to live all by myself in the future (John).

Many of the participants described detailed plans in relation to what they wanted for their future. Andrew, a 21-year-old young man described that when he moved out of home he would live nearby to his relatives:

> I would like my own place. I want to move down south to Dunsborough. I want my own place in Dunsborough. My grandparents are in Busselton and my Aunty is in Margaret River. I want to live down there (Andrew).

Another young man, Jack described his future plans:

> I want a house near the beach with a movie theatre in the house (Jack).

The process of leaving home is an important factor in transitioning into adult life and is most frequently associated with achieving independence [61]. At this time young adults begin to establish an identity separate from their parents [38]. When confronted with the task of leaving home, typically developing young adults experience conflicting feelings, from excitement to fear of not being able to cope with everyday tasks and maintain meaningful relationships [62]. However, as with other young adults with intellectual disability [13] the focus of participants in this study was on leaving home only, often without concern for household management and responsibility. If young adults with intellectual disability are not appropriately supported in their independent living they may experience difficulties in their daily activities of self-care, personal safety and money management [54]. Although they strive for an independent identity, young adults with intellectual disability often continue to rely on their parents for support, and never truly separate their identity from that associated with their parents [13].

Overall the young adults in this study were excited about their futures. They had many hopes and dreams which they aimed to fulfil as adults. Achieving these was for them centrally important in having a ''good life'' as an adult. These findings highlight the importance of not only supporting young people with Down syndrome to shape their own futures with regards to their relationships, community participation and independence, but also to help them to reach their dreams.

## Discussion

Overall, the findings from this study revealed that the participants' life perspective was positive, with a general consensus of, 'I have a good life''. Throughout this study they described their desires for autonomous behaviour, independent living and the recognition of their status as a young adult. These desires for achieving such milestones are similar to those of their peers, including the rights to the same life opportunities. Participants' desires can be explained according to Erikson's developmental stages, whereby the participants were experiencing conflict between developing their adult identities, whilst also trying to re-establish their roles and relationships in the context of family, friends and society [34]. Our findings reflected their conflicts in identity formation, as participants considered themselves to be young adults, but felt their parents at times, inhibited their independence. Previous research has described the transition into adulthood for young adults with Down syndrome as a period of confusion and stress for families [6].

This research highlighted that for young adults with Down syndrome a ''good life'' was influenced by most components of the ICF. Environmental factors which were identified included supportive social networks, family relationships and accommodation/independent living options. Activity and participation components included employment and education opportunities, involvement in recreation and leisure activities and opportunities to drive. An interesting finding was while all participants had Down syndrome, none of the individual or group discussions mentioned impairments of body functions and structures. Rather discussions focused on the desire to be full and active participants in range of life areas. Parents were described as both assisting and hindering the participation of their children, and the young people needed more opportunity for discussions around sexuality, relationships and independent transport.

Findings from the current study must be interpreted in the context of the limitations of our research. This research involved a small, purposive and convenient sample of young adults with Down syndrome. In interpreting the findings, it is not proposed that the experiences or views expressed by these young adults reflect those of all young adults with Down syndrome, but rather the findings represent a first attempt to understand what a good life means from the perspective of a small group of young adults with Down syndrome. While the researchers used novel approaches to data collection including the use of colourful pens and poster-sized sheets for data recording involving these young adults in the research presented challenges, such as maintaining their attention and eliciting their views. The young adults who participated in this study by virtue of their ability to interact in a group and engage with the researchers had good communication skills. Future research should explore ways of obtaining the views of young adults with intellectual disability who experience challenges in this area. The majority of research has examined the perspectives and reflections of quality of life for people with Down syndrome, from either the parental or carer perspectives [5,12,13]. In contrast, the present study has examined well-being from the perspective of young adults themselves, examining their views and perceptions on the barriers and facilitators to their participation. Research of this kind reduces the marginalization of people with intellectual disability and gives voice to their views.

Findings from the current study which has specifically involved people with Down syndrome have indicated many recommendations that could be integrated into models of service delivery for all young people with intellectual disability, at the time of transition from school to post-school. Areas for future intervention include services aimed at training and attaining employment, life skills training and encouragement of self-determination and education regarding managing relationships with parents, friends and intimate partners. This study has highlighted that although the medical challenges for increasing life expectancy have been largely addressed for people with intellectual disability, the task now for health professionals is to equally match life expectancy with purpose and quality for these individuals.

## Acknowledgements

We wish to thank Down Syndrome WA for assisting with recruiting participants. We gratefully acknowledge the participation of the young adults in this study, as well as the cooperation and assistance of their parents and the staff.

## Declaration of interest

The authors report no declarations of interest.

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## APPENDIX A: INTERVIEW GUIDE

### What makes a "good life" from the perspective of young adults with Down syndrome

(1) How do you start your day?
(2) What happens after that? What do you do for the rest of the day?
(3) What makes you feel happy?
(4) What makes you feel sad?
(5) What are your favourite things to do? What does your favourite day look like?
(6) What helps you do the things you want to do?
(7) What stops you from doing the things you want to do?
(8) What makes a good life? What do you enjoy most about being a young adult?