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Perceptions of Down Syndrome: A growing awareness? Investigating the views of children and young people with Down Syndrome, their non-disabled peers and mothers.

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Institute of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

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# Abstract

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A body of literature has examined the understanding adults with intellectual disabilities have of their disability, their awareness of stigma and experiences of stigmatised treatment. The findings across these studies have however been difficult to reconcile. While a number of researchers reported that participants did not appear to be aware of their disability, others found that participants were aware of their disability and were sensitive to the stigmatised treatment they received from others as a result. The methods used by previous researchers have been largely verbal and it is suggested that such methods may have placed constraints on the abilities of people with intellectual disabilities to express themselves. Thus, the mixed findings may in part be accounted for by the reliance on verbally based methods of enquiry.

As a result of the previous research having been carried out with adults, little is known about the perceptions children with intellectual disabilities have of their disability or their awareness of social stigma. It is important to know about children's perceptions because early self-perceptions may have an enduring impact on a young person's mental well-being. Further, gaining insight into how the self-perceptions of children with intellectual disabilities develop during childhood may help to inform interventions designed to target the development of positive self-perceptions in children with intellectual disabilities. This thesis will focus on children with Down syndrome. Down syndrome is a chromosomal disorder and one of the most common causes of intellectual disability (Carr, 1995). People with Down syndrome have distinctive facial features, which make them immediately identifiable to others and may mean that people with Down syndrome identify themselves as different from others.

The key questions addressed by the present research are: Are children with Down syndrome aware of Down syndrome and do they hold particular feelings about it? The present study was conceptualised as an exploration of children's rudimentary awareness of their disability and the social stigma attached to it. In order to explore children's perceptions, a mixed method approach was chosen.

The quantitative component of the study developed pictorial methods to investigate the awareness and views children with Down syndrome hold of Down syndrome. Children completed three experimental 'tasks' that involved colour illustrations and photographs of

unfamiliar children, some of which depicted children with Down syndrome and some in which children had no visible disability.

Twenty-eight children with Down syndrome took part. There were two age groups; a younger group aged 8 to 12 years old (n= 10) and an older group aged 13 to 17 years old (n=18). The purpose of the two age groups was to explore potential differences in awareness shown by participants with different amounts of social experience. A comparison group of children with no disability allowed the researcher to investigate whether having Down syndrome led to differences in task performance. However, since children with Down syndrome have at least some degree of intellectual impairment, it was necessary to control for cognitive development and age separately. A cognitive ability control group enabled the researcher to ensure, as far as possible, that any differences in task performance that did occur could not be attributed to differences in participants' cognitive ability. The chronological age control group was used to help ensure that potential influence of social experience and learning, acquired with age, were also controlled for. Therefore, two groups of non-disabled participants were recruited; one group were the same chronological ages as participants with Down syndrome and the other were younger in chronological age, in the hope that their verbal ability would match that of participants with Down syndrome. However, despite their younger age, the non-disabled children scored consistently higher than participants with Down syndrome on the measure of verbal ability. Consequently, a verbal ability control group was unfortunately not achieved. Instead, the non-disabled participants were split into three age groups. The first group were younger in age and their verbal ability was closer to that of participants with Down syndrome (n=14). Although not matched on verbal ability, they were still at an earlier developmental stage and served a useful comparison group in this respect. The second group were aged 8 to 12 years old (n= 27) and the third group aged 13 to 17 years (n= 26). These groups served as chronological age-matched controls. The proportion of males and females in the Down syndrome and non-disabled groups were roughly equal.

For the qualitative phase of the study, the researcher interviewed a subsample of the children's mothers' to examine what they thought about their child's understanding of Down syndrome and the social stigma attached to it. Ten mothers of children with Down syndrome took part in 1:1 semi-structured interviews. The transcripts were analysed using Interpretative Phenomenological Analysis.

The responses of children with Down syndrome on the picture tasks indicated that they discriminated between the photographs of children with and without Down syndrome, they preferred to share social activities with the photographed children with no disability, they identified themselves as similar to the photographs of non-disabled children and they had less positive views about the photographed children with Down syndrome than those with no disability. Participants with no disability also demonstrated a similar bias in favour of non-disabled children during the tasks. Both participants with Down syndrome and non-disabled participants had positive views of themselves, although those with Down syndrome were slightly less positive about themselves than their non-disabled peers. The key finding from the experimental studies was the bias shown by all children in favour of photographs of children with no disability.

A contrasting picture emerged from the interviews with mothers. They expressed deep concerns regarding their child's growing distance from non-disabled peers as they grew older. Nevertheless, the mothers believed their children were oblivious to their disability or, at most, were aware of it but viewed it as inconsequential. Mothers reported waiting for their child to take the lead with regards discussing Down syndrome but most reported that their children rarely asked questions related to their disability and, as a result, it was rarely a topic of conversation. A sense of responsibility to talk to their children about their disability was accompanied by deep anxiety over what was best for their children regarding when and how to tell them about Down syndrome.

This research has highlighted that children with Down syndrome may be more aware of their disability and how Down syndrome is viewed socially than has been appreciated. It underscores the importance of giving children with communication difficulties a way of expressing their views. Future research should investigate the development of children's self-perceptions in relation to disability and inform ways of investigating children's growing awareness disability and related social attitudes. Such research could have an important role to play in fostering more positive ways of thinking about Down syndrome and equip them to deal with social stigma.

# Declaration

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“I hereby declare that I am the sole author of this thesis, except where the assistance of others has been acknowledged.

It has not been submitted in any form for another degree or professional qualification.”

Karen A. Deakin

March, 2014

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# Chapter 1: Introduction

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The aim of this chapter is to give a broad outline of who people with intellectual disabilities are and what it means in today's society to have an intellectual disability. The current clinical definition of intellectual disability will be discussed. In doing so, it will be highlighted that, in addition to identifying a group of people who share particular difficulties, the label also refers to a changing social representation. Prevailing ideas about intellectual disability also have repercussions for the services individuals receive. This will be discussed in relation to the provision of education for children with intellectual disabilities. It will be noted that, despite the efforts of policy makers to promote social inclusion, societal views of intellectual disability are largely negative and people with intellectual disabilities remain one of the most excluded groups in our society (Emerson, Graham and Hatton, 2006).

This thesis concerns people with Down syndrome. Down syndrome is the result of a chromosomal disorder and is one of the most common causes of intellectual disability (Carr, 1995). People with Down syndrome have distinct physical features that make them easily identifiable to others (Carr, 1995). Down syndrome has been the subject of an increasing amount of psychological research in recent years, including an attempt to describe the behavioural phenotype associated with it, thereby identifying these individuals' areas of strength and weakness. The findings of this recent research will be outlined and how this work can be used to help inform new research with people who have Down syndrome. Finally, there will be reflection on the social implications of having Down syndrome and the fact that little is known about what such social experience might mean for a child with Down syndrome growing up.

## 1.1 What is intellectual disability?

### 1.1.1 Terminology of intellectual disability

The term used to refer to persons with intellectual disability has varied both historically and geographically. In the United Kingdom today 'intellectual disability' is the preferred term, and this term is increasingly being used internationally (Schalock, 2011). However, there are a variety of terms still in use and, for clarity, these will be briefly reviewed. In the UK, the term 'learning disability' is still used and it is regarded to be synonymous with

intellectual disability. However, in the USA the meaning of 'learning disability' is different and is used to refer to specific learning difficulties, such as, dyspraxia or dyslexia, rather than general developmental delay. In the UK, the term 'learning difficulties' may also be heard. This term, however, can be ambiguous since it has different meanings depending on the context in which it is used. For example, in educational settings the term learning difficulties is often used to describe children who are underachieving at school for a variety of reasons, not necessarily due to intellectual impairment. Thus, while 'learning difficulties' may include children who have intellectual disability, not all individuals with this label will have an intellectual disability (McKenzie and McAlister, 2010). The term intellectual disability will be used throughout this thesis because it is the term most commonly used and understood internationally.

### **1.1.2 Clinical definition and classification of intellectual disability**

Although the language used to refer to intellectual disability has changed, the definition of it has remained fairly consistent over the last 50 years. The definition includes three core elements: limitations in intellectual functioning, behavioural limitations in adapting to environmental demands and an early age of onset (Schalock, Luckasson and Shogren, 2007).

The most commonly used operational definition of intellectual disability today is provided by the American Association of Intellectual and Developmental Disabilities (AAIDD).

According to this definition:

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. (Schalock et al., 2010, p. 1)

The first element, significant limitations in intellectual functioning, is defined as a score on a standardised IQ test of approximately two standard deviations below the population mean (this boundary has been used since 1973; Schalock et al., 2007; Schalock et al., 2010; Schalock, 2011).

The second element concerns limitations in adaptive behaviour. The concept of adaptive function refers broadly to a person's ability to cope with the day-to-day demands of living

and the AAIDD define it as comprising conceptual (e.g. literacy, number concepts and time), social (e.g. interpersonal skill and social problem solving) and practical (e.g. personal care and travel) skills (Schalock et al., 2010, p. 43-44). Limitation in adaptive behaviour is defined as performance that is approximately two standard deviations below the mean on one of the three types of adaptive behaviour (conceptual, social or practical) or on an overall score on a standardised measure of conceptual, social and practical skills (Schalock, 2011, p. 230). One of the leading instruments to measure an individual's adaptive functioning is the Vineland Adaptive Behavior Scales (Vineland<sup>TM</sup>- II; Sparrow, Cichetti and Balla, 2005).

The classification system used in the diagnosis of intellectual disability in the UK is the International Classification of Diseases 10<sup>th</sup> edition (ICD-10; World Health Organisation, 1992). In the ICD-10 it is emphasised that diagnosis should not be made on the basis of test results alone but that, as far as possible, it should be informed by observation of the individual in community settings, clinical information and the views of family and staff members who are closest to the individual and able to report reliably and in detail on their behaviour in everyday life. This is especially important in the assessment of an individual's ability to adapt to the daily demands of the social environment (Mittler, 1992; WHO, 1992). The idea that there are different levels of severity of intellectual disability is commonly accepted (Hatton, 1998). The ICD-10 uses the following classifications of different levels of disability: mild (indicated by an IQ score of 50-69), moderate (indicated by an IQ score of 35-49), severe (indicated by an IQ score of 20-34) and profound (indicated by an IQ score <20). However, in the ICD-10 it is emphasised that the IQ levels only provide a guide of functioning and should not be applied rigidly. One of the reasons for this is that it is recognised that the IQ test cannot provide a precise indication of a person's intellectual functioning because it is inherently biased towards the dominant culture that people with intellectual disabilities may have limited engagement with (Emerson, 1998). Furthermore, an individual's performance on an IQ test depends on their motivation to engage with it. In the case of individuals with an intellectual disability, motivation may be hampered by previous experiences of failure in test situations (Glick, 1999). Thus, while classifications are based on IQ scores, the importance of taking social and adaptive functioning into consideration is also stressed when making judgments about an individual's level of impairment (WHO, 1992).

### 1.1.3 The social construction of intellectual disability

The above operational definition of intellectual disability, focusing on cognitive and adaptive functioning, dominates today in developed Western countries, such as the UK and USA. However, although people with an intellectual disability have at least some support needs reflecting an intellectual impairment, it is also to some degree socially constructed. This means that definitions of a person's intellectual disability are inextricably tied to their particular cultural context and views of what constitutes an intellectual disability will evolve over time as society changes. Indeed, anthropologists believe that what we call intellectual disability today has been recognised and referred to in all cultures and societies in some form or another (Manion and Bersani, 1987). However, the way it has been defined and explained has differed and changed over time, relative to the nature of society and the political and economic context (Manion and Bersani, 1987). The ways in which intellectual disability has been understood has also had important repercussions for the ways people's needs have been catered for and how they have been treated by members of society (Edgerton, 1984).

The notion that the condition 'intellectual disability' exists is often taken as objective reality in society today. As Dexter (1958) eloquently writes, 'the way situations are defined by society as a whole is for the people in that society the realest of realities' (p.40). However, intellectual disability is in many ways a subjective and relative concept in any given society. The relative nature of intellectual disability is especially evident when it comes to 'limitations in adaptive behaviour', one of the core elements that define the construct today. The social environment an individual inhabits depends on the presiding culture; therefore, what is regarded adaptive in one culture may not be in another. Another, more stark, example of just how malleable even a clinical definition such as intellectual disability can be is provided by Edgerton (1993) who pointed out that from 1959 to 1963 the IQ cut off point for the diagnosis of intellectual disability was set at 85. In 1963 the American Association for Mental Deficiency lowered the cut off level to an IQ of 70, in order to reduce the number of people categorised as having an intellectual disability, thereby reducing the financial burden of having to meet their significant needs. Further, Edgerton (1993) reminds us that the whole idea of intelligence as a unified and measurable entity is a fairly recent phenomenon and IQ is a cultural product.

Further, while the sharing of a label implies a degree of commonality, the individuals subsumed under the category label of 'intellectual disability' actually have very different levels of ability and need (Edgerton, 1993). In addition, there is no one aetiology associated with intellectual disability. There are in fact many, some of which are better understood than others. For example, Down syndrome and Fragile X syndrome are common chromosomal causes of intellectual disability that are now easily identified, if not wholly understood. By contrast, there are many individuals diagnosed as having an intellectual disability for which there is no identifiable cause. These individuals tend to have milder impairments (Hatton, 1998). Thus, individuals who actually differ significantly from one another are categorised together and labeled within an umbrella term of intellectual disability. The heterogeneity of the population illustrates that the category label itself is the result of countless individuals over millennia trying to make sense of some people in society who, to some degree, appeared to struggle with daily life. Intellectual disability is then not an objective or fixed entity, but historically situated and culturally derived (Kliewer, 1995).

According to Goodey (2001) the conceptual basis for the definition of intellectual disability that we have today began to emerge during the 17<sup>th</sup> century. However, the three pronged conceptualisation of intellectual disability outlined in the previous section has existed for approximately 100 years (Goodey, 2001). Despite remaining in essence the same since its conception, changes in name and refinements of the underlying constructs have taken place (Berkson and Taylor, 2006; Wehmeyer, Buntinx, Lachapelle, Luckasson, Schalock, Verdugo et al., 2008). For example, in recent years changes in name have reflected a shift in thinking about disability from a condition residing in the individual to a construct reflecting the fit between a person's capacities and the context within which they are expected to function (Schalock, 2011). This shift to a more social-ecological framework also focuses more attention on how individualised supports can be provided to help the individual function in their community (Schalock et al., 2007).

Intellectual disability then does not just reside in the individual, but exists within a particular social and cultural context. This means that who is regarded as having an intellectual disability and how the condition is interpreted has changed over time and varies cross-culturally. The particular nature of the construction of the condition has important implications for how people are treated by society and how their needs are met.

## **1.2 What does it mean to have an intellectual disability today? Education for children with intellectual disabilities**

Education is regarded as a human right; however, it is only since 1975 that this right has been extended to all children in the UK, regardless of the abilities and disabilities they may have (Hayward, McBride, Smith and Spencer, 2005). The shift to include children with intellectual disabilities in education reflects the changing position of people with intellectual disabilities in society. This section will review the recent history of education for children and young people with intellectual disabilities and, in doing so, provide the context within which provision is made for such students in schools today. However, a complete consensus regarding educational provision for children with intellectual disabilities has not yet been achieved and there are ongoing debates as to where and how children with intellectual disabilities' educational needs are best met. It is important to consider the position that children with intellectual disabilities hold within the education system, since school is where children and young people spend a large proportion of their life. In other words, the life experiences of children and young people in school will undoubtedly have a significant impact on them.

The 1970s marked a major shift in thinking about the appropriate care of people with intellectual disabilities. In particular, the 1970s marked the beginning of the end of large institutions used to house people with intellectual disabilities, as they were increasingly recognised to be dehumanising environments (Jahoda, 1995). This period also saw fundamental shifts in attitudes toward provision of education for children with intellectual disability (Willis, 2007).

The previous system, based on the Education (Scotland) Act (1945), had claimed to provide educational opportunities for all. However, the system was based on categorisation and selection. The system recognized nine categories of disability: deafness, partial deafness, blindness, partial sightedness, mental handicap, epilepsy, speech defects, maladjustment and physical handicap. Children who were identified as falling into one of these categories were selected to be educated in special school environments. The particular school they attended depended on the disability they had. Children who were considered severely disabled were completely excluded from the education system and instead attended training or day-care centre establishments (Hayward et al., 2005).

Children with Down syndrome were automatically allocated to training centres, because it was wrongly assumed that they were all severely disabled and deemed to be 'ineducable' (Booth, 1985). It was not until 1975, with the Education (Mentally Handicapped Children) Act 1974, that all children in Scotland were considered eligible to go to school.

The Warnock Committee examined special education in England, Scotland and Wales, and the report that followed (Warnock, 1978) had a fundamental impact on how special education and education generally, developed in subsequent years. The report emphasised that education is a right that all children are entitled to and that the aims of education are the same for all children (Hayward et al., 2005). The concept of a continuum of Special Educational Needs (SEN) was introduced to replace the categories of the 1945 Act. This was a wide concept and the intention was to focus attention on the individual learning needs of all children rather than on particular disabling conditions (Willis, 2007). The report recommended that children's special educational needs be met in mainstream schools, wherever possible. However, there was also recognition that a minority of children would experience significant learning difficulties and required their needs to be met in specialist provision. Thus, the report retained a place for special schools. The recommendations of the Warnock report were enacted by the Education Act 1981. The Warnock report and Education Act served to draw attention away from where a child's needs should be met, to how they should be met in mainstream schools and what resources and facilities would be required (Willis, 2007).

The Warnock report had also identified and endorsed three forms of integration of children with SEN in mainstream schools: locational, social and functional. Locational and social integration referred to children with SEN being physically on the same campus as pupils with ordinary needs and providing opportunities for all the children to interact. Functional integration was the most complex form, with the aim of allowing children with a range of needs to learn together. This placed significant demand on resources, teachers and schools, so much so, that for some children the most appropriate place for their education has continued to be segregated special school (Willis, 2007).

As a result of the United Nations Convention on the Rights of the Child, which was signed by the UK in 1990, and the Salamanca Statement and Framework for Action (UNESCO, 1994), the concept of inclusion was developed and came to replace that of integration. Social inclusion as a wide ranging human right has been an underpinning value of UK



government and Scottish Executive social legislation since the 1990s (Willis, 2007). The term 'inclusion' was increasingly used in official publications and by the end of the 1990s a series of guidelines and reports had been published that explicitly addressed the issue. For example, *A Manual of Good Practice* (SOEID; 1998) provided detailed guidance for all those concerned with the education of children with special educational needs on developing an inclusive approach (Hayward et al., 2005). The notion of inclusion is broader than that of integration. It is also about increasing children's participation in mainstream schools, but also focuses on the changes required to school structures, ethos and practices to remove barriers to children's participation. These barriers may be environmental, structural or attitudinal (Allan, 2010).

The Standards in Scotland's Schools etc. Act 2000 set out expectations for schools and education authorities regarding children's right to education. While the Act was entirely about inclusive practice, two assertions in particular have inclusion at their core. The first was that, by law, every child has a right to education that is aimed at developing his/her personality, talents and mental and physical abilities to their fullest potential. Second, it asserts that the education of all pupils should be provided in a mainstream school. However, the Act also outlined exceptions to the provision of mainstream schooling, which some critics claim weakened the inclusive nature of the Act. It was feared that educators, less supportive of mainstreaming, would use such exceptions as an excuse to reject disabled students (Hayward et al., 2005). The exceptions laid out in the 2000 Act were that a child could be educated elsewhere if their needs would be better met in separate provision, where their presence in the mainstream school would be detrimental to the education of other pupils, or where the cost of educating the child in a mainstream school would be unreasonably high.

In 2004, The Education (Additional Support for Learning) Scotland Act (ASL Act) first came into existence. The ASL Act was intended to further the inclusion agenda introduced by the 2000 Act and emphasised that appropriate additional support must be made available to ensure that all learners are challenged and supported to reach their fullest potential, in order that they become well-developed persons who are full members and contributors to society. As established in the 2000 Act, it assumes this will take place in mainstream schools. The title of the ASL Act was also regarded as significant because it represented a subtle shift in pedagogy; the emphasis was not on the deficits of individuals but on learning, and the duty of the system to provide whatever support was needed to

maximise learning. In the ASL Act, it was recognised that all learners in mainstream education may require support to meet a range of needs and this was a normal part of their education. In short, the ASL Act made provision for additional support in cases where learners require it with their education (Hayward et al., 2005).

Inclusive schooling continues to be pivotal to current educational policy (Willis, 2007). However, legislation is just part of the story, as it can only pave the way towards a fully inclusive education system; how legislation is interpreted and implemented, and how successfully the goals it sets out are achieved depends on the attitudes of educators on the ground (Hayward, et al., 2005).

Studies have shown that teachers are positive about the concept of inclusion (Avramidis, Bayliss and Burden, 2000; MacBeath, Galton, Steward, MacBeath and Page, 2006), although the policy of inclusion has been experienced as challenging. In particular, concerns have been raised as to how it can be achieved in practice and whether inclusion is in every child's best interest. Teachers often report that they feel they lack the training as well as the resources and time required to implement inclusive practice. As a result, they often lack confidence in their ability to deliver inclusive education (Avramidis et al., 2000; Thomas and Vaughn, 2004; Mittler, 2000). Teachers also express concern about the ability of mainstream schools to provide suitable education for some children, namely those with complex special needs (MacBeath et al., 2006). Finally, teachers and their unions have questioned if 'total inclusion' is always in the best interests of some children with SEN or their peers, as they fear the learning environment fails to meet anyone's needs properly because teachers simply cannot accommodate everyone (Allan, 2010). Parents of children with disabilities have also become increasingly concerned about the openness of mainstream schools to accept their child and have reported large variations in practice between different local authorities (Audit Commission 2002; Office for Standards in Education, 2004, cited in Allan, 2010) and have experienced considerable struggle to have their child fully included (MacBeath et al. 2006). There are, however, more positive reports from teachers who have greater experience with children with SEN. These more experienced teachers feel better equipped to manage an inclusive classroom and report more positive attitudes towards inclusion (Avramidis et al., 2000).

Baroness Warnock, regarded by many as the 'architect' of inclusion thanks to the influence of the 1978 Warnock report, declared in a recent pamphlet published by the Philosophy of

Education Society of Great Britain that she thought inclusion had 'gone too far' (Warnock, 2005). Warnock (2005) stated that the concept of SEN, intended to break down barriers, had, in practice, led to a tendency to see all children with SEN as the same, which was unhelpful. She believed that while some children with SEN can be taught easily in mainstream classes, others require more specialist provision, which she maintained could only be provided in a special school setting. Warnock (2005) further voiced concerns about bullying, which she believed to be inevitable in mainstream schools, especially secondary schools. Warnock (2005) stated the belief that, in practice, inclusion had meant that children were physically included but often emotionally excluded. The Baroness' views appeared to reflect some of the concerns voiced by teachers but her pamphlet was met with criticism from people who claim she appeared to be out of touch with the current system and recent research findings. Critics of Warnock believe that while the road to inclusion has been and continues to be rocky, it has often proved successful and remains the ultimate and only right goal (Norwich, 2010).

Clearly, the state of special educational provision for children with disabilities is a contentious topic. The reality of schooling for children with intellectual disabilities and their families is likely to be complex and their experiences varied. Inclusion in a local mainstream school will undoubtedly have benefits and in some cases it may be regarded as a wholly positive experience for all; pupils, families and schools alike. However, it is also likely that for some families, getting their child accepted into mainstream education has been a frustrating and complicated affair. Further, if the child's presence in the classroom is perceived as a challenge for their teachers, the child's experiences of mainstream school may be mixed.

Confronted with the uncertain social reality of children with intellectual disabilities described above, it is remarkable to find that very little research has been carried out looking at their experiences growing up. Investigations into how children's experiences impact upon their perceptions of themselves have a key place in ensuring children's wellbeing.

### **1.3 Down syndrome: The quintessential image of intellectual disability**

Down syndrome is the most common and most easily recognised condition causing intellectual disability (Carr, 1995). Down syndrome occurs in 1 in 700 to 1 in 1000 live births (Stoll, Alembik, Dott and Roth, 1990). The most common type of Down syndrome, accounting for 95% of cases, is standard Trisomy 21 and is caused by an extra chromosome 21. The other types are translocations where only some cells will contain the extra chromosome (Mosaic Trisomy 21; Fidler, 2005; Carr, 1995).

The two sets of characteristics most frequently associated with Down syndrome are a distinctive facial appearance and intellectual impairment. Indeed, it was the distinctive appearance, and in particular the epicanthic fold, that contributed to the identification of Down syndrome by Langdon Down (1866) and his association of people with Down syndrome with the 'Mongoloid' race (Jahoda, 1995). Down syndrome is diagnosed at birth and the facial characteristics mean that the syndrome is easily identifiable to anyone the child comes into contact with from an early age. People with Down syndrome will have some degree of intellectual impairment, though the level of impairment varies from person to person. According to Carr (1988) children and adults with Down syndrome differ from one another in terms of IQ to a similar magnitude to people in the non-disabled population. That is, people's IQs can differ by 50 to 60 IQ points.

Recent behavioural phenotype research has identified a distinct profile of behavioural strengths and weaknesses associated with Down syndrome (Fidler, 2005). Behavioural phenotype research allows for a more fine grained understanding of the abilities and the potential of children with genetic disorders, than that provided by an IQ score (Fidler, Most, Booth-LaForce and Kelly, 2008). Further, even greater understanding can be achieved by investigating how phenotypes develop and change over time (Karmiloff-Smith, 1998).

The Down syndrome behavioural phenotype includes relative strengths in areas of visual-spatial processing, compared with verbal processing (Jarrold and Baddely, 1997; Jarrold, Baddely and Hewes, 1999). In particular, visual memory and visual-motor integration appear to be areas of relative strength (Fidler, 2005; Dykens, Rosner and Ly, 2001). A common test of visual-motor integration requires participants to reproduce a series of

geometric shapes of increasing complexity using a pencil and paper (Developmental Test of Visual-Motor Integration; Beery and Buktenica, 2010). The evidence suggests that children with Down syndrome have particular skills in this area, and are competent in using visual information to inform motor movements.

Children with Down syndrome have been found to demonstrate difficulties with working memory and verbal short term memory. In addition, long term memory for words and pictures has also been found to be significantly difficult for children with Down syndrome (Jarrold et al., 1999; Vicari, Carlesimo and Caltegrone, 1995; Vicari, 2006; Carlesimo, Mirotta and Vicar, 1997). Language delays are characteristic of children with Down syndrome. However, a relative strength in receptive compared with expressive language emerges in children with Down syndrome in the first few years of life and then becomes more pronounced as children enter middle childhood (Miller, 1999). Social functioning has been generally considered to be an area of strength in children with Down syndrome (Gibbs and Thorpe, 1983; Meyers and Pueschel, 1991; Wishart and Johnston, 1990). However, more recent research highlights complexities and subtle differences across a range of socio-cognitive abilities from early infancy onwards that may call this long standing assumption into question (Cebula, Moore and Wishart, 2010).

An important point in behavioural phenotype research is that it shows people with particular genetic syndromes, such as Down syndrome, are predisposed to demonstrate a certain profile of strengths and weaknesses. However, this does not suggest that the profile is inevitable or that it arises in a vacuum determined purely by biology. It may be argued that the cognitive and social strengths and weaknesses a child demonstrates will shape the social environment around them and, in turn, this environment will impact upon the development of the child. Indeed, many researchers emphasise the dynamic, bidirectional and transactional nature of child development (Moore, Oates, Hobson and Goodwin, 2002). This point is illustrated by the findings of a study by Moore et al. (2002). They found that children with Down syndrome showed an early weakness in attention regulation. Mothers appeared to be sensitive to this and responded by adopting a warm but more forceful interactional style, in order to maintain typical levels of attention in their child. The authors suggested that this maternal style was a natural and functional response that, at the time, may have been positive and effective in buffering their child's limitations. However, the mothers' response may have had a negative impact in the longer term, since the child may have become dependent on their mother's regulation of their attention. Thus, such a

response may have had lasting effects on the child's development and sense of agency (Cebula et al., 2010). Research such as this serves to highlight that in an attempt to really understand any behavioural outcome, a developmental and transactional approach is crucial. Recognition of the two-way and interactive influence of both genetic predisposition and environmental factors is critical.

The social environment of children with Down syndrome includes the negative views of Down syndrome and intellectual disability held by society. Children with Down syndrome are stigmatised both for having an intellectual disability and for how they look (Booth, 1985). The way they look also means that they are immediately identifiable to others. It also means that they may be more identifiable to themselves as being different from other people, or that their appearance may quickly become associated with feeling different as it elicits a set of behaviours from others. Many experiences in relation to one's disability will take place in school and given the precarious nature of inclusion, these experiences may be mixed in the mainstream classroom. There is no academic literature on what it may be like to grow up with such a visually identifiable disability. Finding out how children with Down syndrome experience their disability presents a challenge to research, since verbal expression presents a difficulty for most people with Down syndrome. However, the behavioural phenotype outlined above can be used to inform such research. It points to areas that present a particular challenge for children and would be best avoided when trying to obtain insight into their perceptions, and also point to particular areas of strength that can be capitalised upon to better understand children's experiences.

The following section will look at what stigma is by examining how it has been defined, before going on to describe the stigma attached to intellectual disability and Down syndrome. The research literature on the perception of stigma by individuals with intellectual disability will be described, alongside an appraisal of the limitations associated with it. What is missing from previous accounts is an understanding of how experiences of stigma may be mediated by developmental processes. A psychological account of the development of self will be used to shed light on what developmental processes may be involved. Finally, the aims of the present research will be delineated.

## **1.4 Stigma and intellectual disability**

### **1.4.1 Defining stigma: What is it?**

Current perspectives on stigma are rooted in Erving Goffman's (1963) classic consideration of the phenomenon in his book, *Stigma: Notes on the management of a spoiled identity*. According to Goffman stigma is a 'mark' or an 'attribute that is deeply discrediting' and that reduces the bearer 'from a whole and usual person to a tainted, discounted one' (1963, p.3). Crocker, Major and Steele (1998) succinctly proposed that 'stigmatised individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context' (1998, p.505).

Stigma is also a process involving labelling and stereotyping. Goffman (1963) noted that when trying to understand stigma, a 'language of relationships' is more appropriate (1990, p. 13). He observed that stigma is the result of a relationship between an 'attribute and a stereotype'. In other words, the human difference that is deemed socially significant is labelled and becomes a valid way of categorising people. The label then becomes associated with a set of undesirable attributes that together form a stereotype. This process acts to minimise variability among people within the group and maximise difference from the majority, thereby paving the way for those labelled to be regarded as fundamentally 'different', and in extreme cases, less than human (Link and Phelan, 2001; Goffman, 1963). Once a group of people are considered 'different' the justification for devaluing and excluding them is established, and consequently the stigmatised individual experiences a loss of status in society and discrimination. Link and Phelan (2001) further emphasise that power is a key component of stigma. Only some people and groups in society have the power to select who becomes stigmatised and have the resources to make their beliefs prevail. For example, the English colonists of the eighteenth century were only able to stigmatise the Dutch because they held positions of power over them at the time (Link and Phelan, 2001).

### **1.4.2 The stigma of intellectual disability and Down syndrome**

Having considered what stigma is, this section will examine the particular stigma associated with intellectual disability. In his seminal ethnographic study of people with intellectual disabilities who had just left state institutions, Edgerton (1967) clearly identifies cognitive impairment as being a particularly salient stigma.

'Of all the attributes of man, mind is the quintessence; to be found wanting in mental capacity – in general intellectual competence – is the most devastating of all possible stigmata' (1993, p. xxi).

While it is true that much has changed in society since Edgerton's study, intellectual disability is, and has been, one of the most pervasively stigmatised social identities in Western society (Craig, Craig, Withers, Hatton and Limb, 2002). Evidence for such stigmatisation comes from several sources but perhaps one of the most telling is the nature of clinical terms previously used to refer to intellectual disability and how they became terms of insult and abuse (Rosen and Gregory, 1965). For example, the word 'retardation', which was once a clinical term used in the USA, has now evolved into the derogatory term 'retard', a slang term used to denigrate someone. Clinical terms and words associated with a marginalised group often emerge as invectives, because the group is stigmatised and hence the word carries negative connotations. By calling someone a 'retard', the person or object of the insult is equated with the marginalised group and subjected to the effects of that stigma. As a consequence of the term 'retard' having become stigmatised itself, it is now regarded demeaning to those who have intellectual disabilities, their families and friends. In 2002 the American Association on 'Mental Retardation', changed its title to the American Association on 'Intellectual and Developmental Disabilities'. Whilst there were many reasons for this shift in terminology, one of the key ones was the stigma attached to the derogatory term 'retard' (Siperstein, Pociask and Collins, 2010).

Although the most recent, this is not the first clinically derived term of insult to be incorporated into the public lexicon. The formal clinical terms 'feeble-minded', 'idiot', and 'imbecile', previously used by professionals to denote levels of intellectual impairment, have also acquired negative connotations (Switzy and Greenspan, 2006). Indeed, it was the fact that these labels had become terms of insults that advocates fought for the use of less pejorative terms like 'mental handicap' in the UK and 'mental retardation' in the USA to replace them (Goode, 2002). Therefore, the same pattern of clinical terms later becoming used as insults has persisted over time, its history in relation to people with intellectual disability spanning at least a century (Siperstein et al., 2010).

Just as the persistence of the stigma attached to intellectual disability is reflected in the continued pattern of clinical terms being invoked as insults, the stereotypes attached to



intellectual disability also have a long history. Sheerenberger (1983) observed that the stigma of people with intellectual disabilities in the West has been underpinned by a combination of pity and fear, and that such ideas may be traced back to early Christian beliefs. One belief was that people with intellectual disabilities were the innocent children of God. Similarly, Stainton (2008) argues that St Augustine equated people with intellectual disabilities with children and with the idea of 'innocence', since they were held to lack reason and hence responsibility for their actions. In effect, this meant that they were to be perpetually treated like children. A later belief, however, undermined this relative benevolence, since disability came to be regarded as a manifestation of a sin or an evil (Sheerenberger, 1983). Historically, fears have also prevailed about people's sexual deviance or promiscuity (Jahoda, 1995). Notions about the perpetual child-like innocence of people with intellectual disability remain today (Jenkins, 1998). Thus, despite official clinical definitions of intellectual disability evolving, the stigma attached to it appears to echo earlier social constructions.

Down syndrome has a particular history and stereotype. It was first identified by J. Langdon Down in 1866, who, in formulating a classification system of 'idiots' based on the physical features of various ethnic and racial groups, named it 'Mongolism'. He used this term because he thought the epicanthic fold, giving people very distinctive eyes, demonstrated a link with the 'Mongoloid race'. Down (1866) believed that individuals from his categories or 'ethnic varieties', represented throwbacks from an earlier degenerate period in human evolutionary history:

'There can be no doubt that these ethnic features are the result of degeneration'  
(Down, 1887/ 1990, p. 129, cited by Kliever, 1995).

Down (1866) described people with Down syndrome as 'willing and submissive to authority'. However, he later contradicted this by saying, 'they delight in defiance' (Down, 1866, cited by Wishart and Johnston, 1990, p. 409). The idea that people with Down syndrome have a particular personality however has stuck and may still be found in lay attitudes today. Down's characterisation has been elaborated on over the years by other clinical impressions of individuals with Down syndrome. The so-called Down syndrome-personality includes traits such as stubborn, happy, affectionate, easy going, mischievous and fond of music (Wishart and Johnston, 1990; Gilmore and Campbell, 2003). However, despite being predominantly positive, this stereotype is no less potentially damaging, since

it neglects the individuality of the child and sets up expectations of how people with Down syndrome will behave, which in turn influences how others interact with them (Wishart and Johnston, 1990; Gilmore, Campbell and Cuskelly, 2003).

A recent UK study investigating public attitudes towards people with intellectual disabilities suggests that present day attitudes towards people with intellectual disabilities reflect a complex history and remain ambivalent (Scior, 2011). For example, while most lay people surveyed broadly agreed with the *right* of people with intellectual disabilities to be included in society, when asked about their motivation to engage in social interactions with people who have disabilities, people with intellectual disabilities are consistently selected as one of the least desirable groups to interact with (Scior, 2011). Further, whilst generally in favour of inclusion, a small but significant minority favoured segregated education, living and employment for people with intellectual disabilities. These views did not necessarily stem from hostility. In some cases, respondents appeared to be concerned for the wellbeing of the individual or fear that inclusive classrooms will be detrimental to non-disabled children in the class. It has also been suggested that people's reluctance to interact with those who have intellectual disabilities may in some cases stem from discomfort and anxiety about their ability to manage such interactions (Scior, 2011).

Like the stereotypes and attitudes towards people with intellectual disabilities, the stigmatised treatment experienced by this group can take many forms. People experience direct discrimination in the form of verbal abuse and cruel remarks, sometimes on a daily basis (Scior, 2011). Bullying is consistently a major public health concern, reported by both children and adults with intellectual disabilities (Mencap, 2000). Disability hate crime has also been a key focus of the Crown Prosecution Service in the UK (UK Crown Prosecution Service, 2010). However, stigma may not always be as blatant as these direct forms of discrimination. Edgerton (1993) illustrated how stigma can interfere with the flow of social interaction. He described how, once intellectual disability is noticed, a person may reduce his or her communication to a basic level, sometimes converting to a condescending tone or form of 'baby talk'. Often, for fear of causing embarrassment, people assume only the most rudimentary level of knowledge, so much so that the interaction is slowed down to the 'point of virtual cessation' (Edgerton, 1993, p. 191). Another more subtle form that stigma may take is the denial of opportunities that are within an individual's capabilities by well-meaning but over-protective families (Jahoda, Wilson, Stalker and Cairney, 2010). Therefore, the stigmatised treatment faced by people

with intellectual disabilities is varied, pervasive and may be motivated by kindness as well as hostility (Jackman, 1994; Glick and Fiske, 1997). In the case of visible disability, such as Down syndrome, staring is a more subtle but equally distressing form of stigmatisation.

## **1.5 How might stigma impact upon the individual?**

There are various mechanisms through which stigma could impact on the individual (Link and Phelan, 2001). On a practical and material level, direct discrimination can limit a person's access to important life domains, such as, housing, employment and health care, having deleterious effects on psychological and physical health (Major and O'Brian, 2005). Direct prejudice and discrimination in the form of verbal, or even physical, abuse has obvious implications for one's psychological wellbeing. However, the phenomenological experience of being stigmatised can occur by simply being aware of the negative value placed on one's social identity (Crocker et al., 1998). In other words, once a cultural stereotype is in place, simply being aware that one belongs to a stigmatised group may have a detrimental impact on the individual (Link and Phelan, 2001).

According to the classical perspective on stigma advocated by Goffman (1963), awareness that one's social identity is devalued would inevitably have detrimental repercussions for how a person sees him/herself. In this section, Goffman's position will be reviewed, with reference to symbolic interactionism. However, considerable research evidence has mounted that suggests that the effects of stigma are not as straightforward and inevitable as early thinkers believed. Contemporary researchers emphasise the situational factors that mediate the impact of stigma and the strategies that individuals use as agents of their own resilience in the face of stigma (Crocker et al., 1989). Some of these strategies will be considered to illustrate the complexity of the relationship between stigma and the self. From this discussion, it will be concluded that individual coping strategies that mediate the impact stigma has on self-esteem need to be further investigated. Moreover, what is missing from contemporary work on stigma is a developmental perspective and proper consideration of the effects of stigma across the lifespan.

## 1.5.1 Classical perspectives on how stigma impacts upon the individual

Goffman (1963) defined a stigma as 'an attribute that is deeply discrediting...' (p.13) and one that becomes an individual's 'master status', such that, 'an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us' (p.15). Thus, stigma is social in origin and is about others' reactions to the attribute rather than the attribute itself. For Goffman (1963) the stigmatised individual was thought to be adversely affected to the extent that they were aware of the social stigma associated with the attribute they have, and he assumed that, thanks to socialisation processes, the individual would be very sensitive to their stigma. In Goffman's (1963) words, '...the standards he has incorporated from the wider society equip him to be intimately alive to what others see as his failing...' (p.18) and '...it demonstrates the more important fact that a stigmatised person is first of all like anyone else, trained first of all in others' views of persons like himself...' (p.160)

According to Goffman (1963), knowledge regarding one's stigma would result in feeling shame and the individual would be driven to manage their stigmatised identity by using strategies to conceal and control the information others received about his/her stigma. In short, for Goffman (1963), stigma constituted a fundamental threat to the individual's selfhood, 'Given that the stigmatised individual in our society acquires identity standards which he applies to himself in spite of failing to conform to them, it is inevitable that he will feel some ambivalence about his own self' (p.130).

Goffman's (1963) theoretical standpoint originates in the symbolic interactionist framework of Cooley (1902) and Mead (1934). Both of these writers placed emphasis on the importance of one's ideas about how others see and/ or judge the self. Cooley (1902) referred to the 'looking glass self', by which he meant that an important determinant of one's self is, 'the imagination of our appearance to the other person; the imagination of his judgement of that appearance, and some sort of self-feeling, such as pride or mortification' (p.184). Mead (1934) also emphasised that how one thought other people saw the self was important to the development of one's self-concept, but in contrast to Cooley (1902), he stressed the development of the self-concept during childhood. Mead describes a two stage process of development of self awareness, the first being 'play', where the child

experiments with different roles and pretends to interact with him/herself, and then 'game', where the child learns the expectations of the 'generalised other'. As Mead himself says, '...the result of the given individual taking the attitudes of others towards himself, and of his finally crystallising all these particular attitudes into a single view or standpoint which may be called the 'generalised other" (p.90). Therefore, one learns to judge the self as one is judged by his/her culture. In the case of stigma, this theory implies that with the internalisation of one's cultural value system, self-derogation is inevitable.

Therefore, according to classical theories of the relationship between stigma and the self, being aware that others view the self negatively because of an attribute one possesses inevitably has negative effects on one's own view of self. This section will now move on to review more recent considerations of the relationship between stigma and self. Researchers in this area have used measurements of the construct self-esteem to examine this relationship.

### **1.5.2 Contemporary perspectives on how stigma impacts upon the individual**

Following a review of the empirical research looking at the link between stigma and self-esteem, Crocker and Major (1989) concluded that, contrary to what symbolic interactionist theory predicts, individuals do not appear to inevitably suffer low self-esteem as a consequence of being a member of a stigmatised group. As a result of this review, Crocker and Major (1989) proposed that the symbolic interactionist account of Goffman (1963) was simplistic and did not take full account the many factors involved and the possible strategies individuals could utilise to protect their self-esteem.

The field today is dominated by identity threat theories of stigma (Crocker et al., 1998; Major and O'Brian, 2005). Proponents of these theories continue to consider the self as socially constructed. These theorists also tend to assume that stigmatised individuals are aware of and develop the same understandings of their identity that prevail in society, through prior experiences and exposure to the dominant culture. This means that the individual is then aware that they are devalued in the eyes of others, aware of the dominant cultural stereotypes surrounding their identity and recognise that they could be victims of discrimination because of their stigmatised identity (Crocker et al., 1998). However, these

theorists highlight the complexities involved in how stigma impacts upon the individual and the strategies people use to manage the threat it poses to their identity.

A distinction is made between social identity, 'that part of an individual's self-concept which derives from his knowledge of his membership of a social group (or groups) together with the value and emotional significance attached to that membership' (Tajfel, 1981, p. 255) and personal identity, 'one's sense of having unique characteristics different from everyone else' (Turner and Reynolds, 2001). The key premise of identity threat theories of social stigma is that awareness that one's social category is devalued poses a threat to the individual's social identity, and hence their overall self-worth. The degree to which awareness of one's membership of a devalued social category poses a threat to one's self-esteem first of all depends on how central that particular category is to a persons' social-identity. Individuals who regard their stigmatised social identity as a central part of their overall social-identity are more likely to perceive it as a major threat to their overall self-worth.

In the event of identity threat, people do not passively absorb the negative views that society holds of their social identity but instead engage in a wide variety of strategies to maintain, protect and enhance their self-esteem (Major and O'Brian, 2005). People cope with stigma-induced identity threat in a variety of ways. However, this section will focus only on those particularly useful for people with intellectual disabilities. According to Crocker et al. (1998) an individual may deal with the identity threat posed by his/ her membership of a stigmatised group by disengaging their self-esteem from domains on which that group is stereotypically thought to perform poorly on. They suggest that an individual may permanently 'dis-identify' with a given domain, particularly when the nature of their stigmatising condition makes success in this domain very difficult. Therefore, in effect, performance in this domain ceases to have any bearing on their self-esteem. For example, a young person with an intellectual disability may dis-identify with academic endeavours, since the social representation of intellectual disability dictates that aspiring to success in this domain would be futile.

Stigmatised individuals may also manage identity threat through the social comparisons they make with other individuals (Crocker et al., 1998). Social comparisons are an important source of information about the self and a key determinant of affect and self-esteem. There is considerable evidence that if one believes one compares favourably to

others, self-esteem is enhanced. However, if one perceives comparisons to be unfavourable, self-esteem is diminished (Tajfel and Turner, 1986). Because members of stigmatised groups are by definition disadvantaged and likely to compare unfavourably with the dominant group on a number of dimensions, the stigmatised person is vulnerable to identity threat via social comparison, because of the greater availability of 'superior' social comparison targets. Yet, Crocker and Major (1989) emphasise that people are not passive victims of the social comparisons afforded by their social environment. Instead, they can actively use social comparisons to maintain and even enhance their self-esteem. One way in which stigmatised individuals can manage the threat of unfavourable social comparisons is by choosing to restrict their comparisons to people who share their stigmatised identity (Crocker et al. 1998). Individuals may deliberately avoid comparisons with advantaged group members because they know such comparisons would have painful consequences for self-esteem (Brickman and Bulman, 1977). It is also suggested that this tendency to compare one's self with similarly stigmatised others will be particularly pronounced for dimensions of self-definition that are important or self-relevant and hence more likely to effect self-esteem (Crocker and Major, 1989). For example, if an individual has chosen to base self-worth on their sporting ability, they will be more likely to protect this aspect of self definition by comparing themselves with others who are inferior in this domain.

Thus, although the contribution of reflected appraisals to the self-concept continues to be recognised, contemporary researchers propose that the relationship between stigma and self-esteem is mediated and moderated by many factors, including strategies that individuals use to protect themselves against the potential detrimental effects of stigma (Crocker and Major, 1989; Crocker et al., 1998). While recognition of these complexities adds to our understanding of how member of stigmatised groups are effected by stigma, what is missing from the social-psychological perspective is a consideration of developmental issues. Developmental factors may have bearing on how members of stigmatised groups experience and deal with stigma. For example, for those who grow up belonging to a stigmatised group, stigma may impact upon them differently across the lifespan. The advancing cognitive and social abilities of the developing child may lead to an increasing awareness of themselves as stigmatised. Moreover, a lack of certain abilities at younger ages may hinder the use of coping strategies to protect the self. More fundamentally, when and how children become aware that they have a stigmatised identity is not addressed in the existing literature.

## 1.6 Adults with intellectual disabilities: Experience of stigma

This section will review a selection of key studies in the literature on adults with intellectual disabilities' awareness and experiences associated with being stigmatised. Davies and Jenkins (1997) carried out semi-structured interviews and participant observation with adults with intellectual disabilities and their support workers. In approaching this issue these authors aimed to investigate the relationship between individuals' group identity as 'learning disabled', as assigned by society, and their personal identity. In particular, the authors sought to find out to what degree the participants' group identity had been internalised or incorporated into their personal identity. The majority of participants appeared unaware of their social identity as learning disabled. When asked to discuss their understanding of terms relating to 'mental handicap' a large proportion responded with 'complete incomprehension' (p. 98). The second largest proportion of participants did provide some definition of such terms, but defined them in such a way so as to exclude themselves. Despite being apparently oblivious of their intellectually disabled label, the participants were very conscious of the impact their disability had on their lives. For example, participants described how they felt restricted, had difficulties finding a job, learning to drive or obtaining a car. The participants also reported difficulties in finding romantic partners and found it very painful to be told by their parents that they could not become parents themselves. Thus, in terms of their experiences, their membership of this social category was very real to them, despite knowledge of the discourse and stigma surrounding it appearing to be absent. Davies and Jenkins (1997) concluded that since participants were unaware of the discourse and stigma around learning disability, there was no reason to think they had internalised such labels or that their identity was affected by them. The authors attribute the incongruence found between the participants' social identity and personal identity to the way parents and support workers controlled their access to information.

Todd and Shearn (1997) also described how parents of adults with an intellectual disability controlled the information their offspring received about disability and the stigma attached to it. Although parents keenly felt the stigma attached to their child's disability, they carefully protected their offspring against becoming aware of it, believing it to be too painful for their offspring. The strategies that parents used to prevent their offspring from



becoming aware of disability included avoiding the use of labels relating to intellectual disability in their presence and supporting their offspring's belief that they were no different to others. Parents appeared to create what Goffman (1963) referred to as a 'protective capsule' for their children. The majority of parents believed that their efforts had been successful and their offspring had not acquired an understanding of themselves as intellectually disabled. Thus, parents were important mediators of the relationship between their offspring and wider society.

The findings of Todd and Shearn (1997) are consistent with those of Davies and Jenkins (1997), in that there appeared to be a lack of congruity between individuals' self-identities and their stigmatised social identity, a disparity that seemed to stem from the practices of significant others. For this reason, Todd and Shearn (1997) concluded that 'secrecy and collusion' remain significant features of the lives of adults with intellectual disabilities and, as a result, individuals are not only unaware of their actual limitations, but also the social stigma attached to them.

In contrast, several studies have found that people with intellectual disabilities have experienced stigmatised treatment and are aware of both their actual limitations and their stigmatised identity. Mest (1988) carried out a focus group study of the views of five intellectually disabled adults. The focus group interview schedule was loosely structured around the topics of employment, friendships and leisure time, but also aimed to elicit their views on their disabled status within society. These participants were aware of the diagnostic labels applied to them and of the related stigma. Participants acknowledged that others treated them differently and described experiences of stigmatising treatment such as being ridiculed by people in the community.

Jahoda, Markova and Cattermole (1988) conducted semi-structured interviews with adults with an intellectual disability who all lived at home with their parents and attended Adult Training Centres for people with disabilities. Interviews were again roughly structured around their social life, autonomy, 'handicap' and stigma. All participants reported having experienced abuse or rejection by non-disabled peers. Further, they were aware of the stigma associated with having been identified as 'mentally handicapped' and their attendance of specialist services. Stigma featured prominently in participants' accounts of themselves in relation to non-disabled people. In addition, participants were painfully

aware of their limitations and the way that parents treated them differently from siblings as a result.

In a second study, Jahoda and Markova (2004) explored the views of two groups of adults with intellectual disabilities. The first group were moving from their family home to more independent living arrangements, while the second group were about to move from a long stay hospital to live in the community. Both of these groups were acutely aware of the stigma they experienced as a result of using specialist services. The adults who resided in the long stay hospital were concerned about how their association with the hospital would impact upon their acceptance in the community. This is particularly significant, as they appeared to be sensitive to stigma despite having lived in an environment isolated from the wider society where one could have been presumed to have been 'sheltered' from stigma. Craig et al. (2002) reported that a group of adults living in supported accommodation in the community were aware of the stigma attached to them as a result of their disability. They held a focus group with six individuals with intellectual disabilities and also surveyed the attitudes of their service provider staff. The researchers sought to explore the relationship individuals have with their intellectually disabled identity and the influence that service provider staff exerted in this relationship. The participants' behaviour during the focus group led the researcher to conclude that they were aware of their disability and the stigma associated with it, since they looked very uncomfortable when it was alluded to during the discussion. In contrast, however, the staff reported that they did not believe the participants with intellectual disabilities saw themselves as disabled. Staff said that although they felt it was important to give individuals a chance to talk about their disability, they were anxious that doing so would cause their service users distress. As a result, staff found the issue difficult to address and tended to avoid it. In addition, many staff members felt that the relatives of people with intellectual disabilities did not want them to bring up the topic.

In conclusion, the literature on adults with intellectual disabilities' awareness and experiences of stigma is somewhat conflicting. The reasons underlying this are unclear but the varied methods used probably contribute to the mixed findings. People with intellectual disabilities often have difficulties with expressive verbal communication. Therefore, relying on open ended interviews and focus groups may limit individuals' ability to express their thoughts and feelings about disability. When considering how to investigate how young people with intellectual disabilities develop a sense of difference or an awareness of

stigma, the literature concerning the development of self-concept may provide a useful starting point.

## 1.7 Psychological perspective on the development of self

Lewis (1990) suggests that the formation of an identity or self is one of the core developmental tasks of a social being. Developing a sense of self is a protracted achievement, progressing through several levels of complexity through the lifespan. In his seminal writing on the self, James (1890) conceptualised the self as comprising two parts: the self as subject (the 'I-self') and self as object (the 'Me-self'). He defined the I-self as the actor or knower and the Me-self as the object of one's knowledge or the sum of what is known. The 'Me' corresponds to the self that is identified, recalled and talked about, and is what is generally known as the 'self-concept' (Rochat, 2001; Harter, 1999).

The duality of self that James (1890) identified continues to feature prominently in writing on the self today (Lewis, 1990, 1991, 1994; Harter, 1999). Thus, in a similar fashion, Lewis (1990, 1999) distinguishes between the 'machinery of self' and 'idea of me'. Lewis (1994) describes the 'machinery of self' as subjective self-awareness, as attention is directed away from the self to external objects, people and events (Harter, 1999). The 'machinery of self' comprises basic motor-perceptual processes (Lewis, 1999). Lewis (1991) describes the 'idea of me' as objective-self awareness, since the self is taken as the object of one's attention. This is the aspect of self that not only knows, but knows it knows (Lewis, 1999).

The 'machinery of self' is thought to be present at birth, or shortly after (Lewis, 1994). An early feature of the 'machinery of self' is the ability to differentiate between oneself and other persons, and this is achieved by 3-months of age (Lewis, 1994). Thus, from the beginning the self is inherently social, since knowledge that one is separate from others presupposes at least some social awareness (Durkin, 1995). Indeed, for Lewis (1999), learning about the self is inextricably linked to learning about other persons. In this sense, Lewis and his colleagues follow in the footsteps of the Symbolic Interactionists Mead (1934) and Cooley (1902); they believe that knowledge of the self and others are dependent on one another: 'I cannot know another unless I have knowledge of myself' (Lewis and Brooks-Gunn, 1979, p. 2). This early self continues to develop throughout infancy as the child interacts with both the physical and social environment (Rochat,

2001). However, it is not until the 'idea of me' emerges that the child is able to reflect on the knowledge of self and others they have acquired (Lewis, 1999).

The idea of 'me' aspect of self has received the most research attention (Harter, 1999). The methodological procedure used extensively to measure the onset of the 'idea of me' involves observing infants' reactions to images of themselves in a mirror (Lewis and Brookes-Gunn, 1979). During the procedure, mothers were asked to surreptitiously smudge the nose of their child with rouge. The infants were then placed in front of a mirror and researchers measured the amount of 'nose directed behaviour' the infants displayed. Infants at 1 year old showed an interest in their mirror reflection, by smiling and cooing; however their responses were no different to their own reflection than to images of other infants. At around 15-18 months old a minority of infants began to display self-directed behaviour, by touching their own noses, and by 21 and 24 months old most infants reached for their own noses (Lewis and Brookes-Gunn, 1979). Self-referential behaviour is taken as evidence that the child has recognised themselves as the object of their experience, through their own physical features. According to Lewis (1994) the verbal equivalent of such behaviour is, "that's me" and thus signals the beginning of an 'idea of me'. Thus, at around the age of 15 to 18 months old infants reach a developmental milestone that enables them to view themselves as the object of their attention. This is also the time that children begin to develop language and use personal pronouns (Lewis, 1994). The self-system, including the 'machinery of self', continues to influence the child's behaviour and is elaborated on as the child learns and interacts with their environment. The content of the 'idea of me' will depend on the child's emerging cognitive capacities as well as socialisation demands (Lewis, 1994). In addition, in the tradition of Mead (1934) and Cooley (1902), it is recognised that the idea of 'me' is also influenced by the qualities of the social interactions the individual experiences and the wider culture they inhabit (Harter, 1999).

In the next section, the developmental sequence with which children's 'idea of me' becomes more sophisticated will be outlined, paying particular attention to those ways of understanding the self that may be implicated in children's awareness of the self as socially different or stigmatised.

### **1.7.1 Developing an awareness of self as different: What the psychological literature suggests**

It is generally accepted that the 'idea of me' depends on the cognitive abilities of the individual and thus its development is age-normative (Lewis, 1990; Harter, 1999). As one would predict, it has been found that infants with Down syndrome display self-referential behaviour in response to the rouge task at a later age than non-disabled infants, depending on their level of cognitive development. Mans, Cicchetti and Stroufe (1978) found that it was not until 3 to 4 years old that the majority of infants with Down syndrome engaged in self-directed behaviours. Those with greater cognitive abilities achieved the milestone earlier than those at a lower cognitive level.

### **1.7.2 Self-identification with social categories**

One of the first ideas about 'me' to develop relates to how the social world may be categorised along the dimensions of age and gender. By the age of 2-years old children begin to categorise themselves and others along these social dimensions and their ability becomes more proficient with age (Lewis and Gunn-Brooks, 1979; Lewis, 1990). For example, Slaby and Frey (1975) reported that 2 year olds were able to label their own gender identity correctly. As their abilities advanced, they realised that gender remains constant throughout life at ages 3 to 4 years old. Then, at ages 6 to 7 years old they were able to understand that even if someone's external appearance changes, for example a girl wears boys clothes, they remain the same gender.

Another socially significant way of defining the self is according to ethnicity. According to Aboud (1988), the majority of research suggests that this ability begins to emerge in white children around the age of 4 years old and by age 6/7 years old the majority can accurately identify their ethnicity. The percentage of Black and Hispanic 4 year olds who correctly identify their ethnic identities tends to be lower. However, by 6 to 7 years old they also appear to have acquired this ability (Aboud, 1988; Madge, 1976). The nature of the social environment has been implicated in children's delayed knowledge of their ethnicity. Katz (2003) suggested that children's proficiency with gender labels stems from the fact that gender is so readily talked about with children as they grow up. By contrast, ethnicity is mentioned less frequently and parents vary as to the degree to which they feel ethnicity is a socially acceptable thing to discuss with their child (Katz, 2003).

The research briefly described above about emerging identities suggests that young children are inclined to organise their social world into categories. Therefore, the availability of information about disability may help to determine how quickly children develop an idea of a social category like 'Down syndrome' and whether or not they regard themselves as being part of such a group.

### **1.7.3 Self in terms of higher-order traits**

The self-descriptions of young children aged 3 and 4 years old tend to focus on concrete observable features of the self (Damon and Hart, 1988). These may be physical attributes ("I've got black hair and brown eyes"), activities ("I can run real fast"), social ("I have a brother called Jason") or psychological ("I'm happy"; Harter, 1999). Young children also describe their likes and dislikes and again focus on those that are observable ("I like pizza"). At this age, children's self-descriptions are also differentiated and isolated from one another, as they lack the ability to integrate their self-descriptions coherently across domains (Harter, 1999). During the period 5 to 7 years old, children begin to organise and combine self-perceptions into higher order sets. However, it is not until the ages of 8 to 11 years old that children can think of themselves in terms of trait labels and integrate self-representations to form higher-order generalisations. Hence, by this age, the self is now likely to include trait descriptions (e.g. smart or dumb). The ability to construct higher-order concepts also means the child can construct a sense of global self-worth. Research suggests that although young children may not be cognitively or verbally able to construct a global concept of their self-worth, they can experience low self-esteem and it can be seen in their behaviour (Harter, 1990). For example, behavioural displays of confidence, curiosity, initiative and independence all point to high self-esteem, while an absence of these behaviours is suggestive of low self-esteem (Harter, 1999).

Thus, young children with Down syndrome may notice the facial features associated with people with Down syndrome. However, it is likely that this feature of themselves will remain separate from their views about other aspects of self. Likewise, this research suggests that if children notice they are not good at things, their insights into their lack of competence in various domains will remain disconnected and it will not be until later when they are 8 to 11 years old that they will begin to integrate their perceptions into one overall notion of a general lack of ability or seeing themselves as 'stupid'. Similarly, the

connection between having Down syndrome and intellectual disability may not emerge until these later years.

#### **1.7.4 Social comparisons**

According to Harter (1999), young children's (3 to 4 years old) ideas about themselves tend to be unrealistically positive and they tend to overestimate their abilities. This is partly because they still lack the ability to differentiate between ideal self-attributes and those that are real. Children's inflated ideas about themselves also stem from their inability to compare their own performance to that of others. The ability to attain information about the self via social comparison is thought to develop around middle childhood (roughly 8-11 years old; Frey and Ruble, 1990). Social comparison may have a negative impact on the self-perceptions of children with intellectual disabilities. For example, if a child attends a mainstream school where the only opportunities for social comparisons are with non-disabled peers, the information gleaned from such comparisons may be the first indications that they are lagging behind academically or are different from their peers (Jacobs, 1983; Renick and Harter, 1989). Indeed, the potential detrimental effect of social comparisons with non-disabled peers on the self-perceptions of children with intellectual disabilities is a key issue in the debate about the value of including children with intellectual disabilities in mainstream education. Of course, social comparisons are not restricted to school settings and may also be carried out with siblings at home. Such comparisons may result in children with intellectual disabilities becoming aware of not being able or allowed to do things that siblings do, such as visit the park without a parent.

#### **1.7.5 Appreciating the perspectives of others**

Slightly before the age of 2 years old children begin to engage in 'social referencing', that is, they look to adults to guide them in responding to ambiguous events (Barrett and Campos, 1990; Harter, 1999). Also at this age, children begin to anticipate the reactions of adults to their behaviour. For instance, children look for the positive reactions of adults to success on a task (Stipek, Recchia and McClintic, 1992). Children's cognitive advances in perspective taking between the ages of 5 to 7 years old enable them to appreciate others' evaluations and views of them more fully (Selman, 1980; Harter, 1999). By the ages of 8 to 11 years old children become more aware of the attitudes others hold towards them. Moreover, then children are able to reflect on others' views and the implications for themselves. While these social-cognitive advances may play an important role in children's

developing understanding of the social world and relationships, for children with an intellectual disability such social awareness might increase their vulnerability to the condescending or negative attitudes of others (Harter, 1999).

Learning to appreciate the perspectives of others coincides with children developing the ability to feel shame, when they believe their behavior has not lived up to the standards of others (Harter, 1999). Shame is a self-conscious emotion. Therefore, it is an affective reaction to the self and the outcome of self-reflective activities. Feelings of shame can be accompanied by a desire to hide from others, low self-worth and even feelings of depression and hopelessness (Harter, 1999; see Higgins, 1987).

According to Lewis (1994), a rudimentary form of shame emerges at the same time as self-referential behaviour in the rouge on the nose task and hence with the development of the 'idea of me'. Rudimentary forms of shame appear to emerge as early as 2-years old and is manifest in children's behavior. For example, Stipek et al. (1992) reported that children of 2 years of age turned away and hunched their shoulders when they were unable to complete a task in front of adults. Thus, behavioural displays of shame include avoidant postures and gaze aversion (Harter, 1999). Kagan (1984) interestingly reported that young children looked distressed when they watched an adult perform a task they would be unable to copy. This was interpreted as implying they were aware of their lack of competence to achieve the standard set out before them.

After the age of 3 years children appear to take their appreciation of adults' standards a step further by evaluating their performance and reacting emotionally to their success or failure, even in the absence of adult reactions (Stipek et al., 1992). A bit later, as their verbal skill increases, shame can be identified in the comments children make about themselves, such as "I'm bad at catching a ball" or "mum doesn't like it when I do that" (Harter, 1999).

According to Harter (1999), it is not until 8 and 9 years old that children have the cognitive ability to reflect on the feeling of shame in an adult sense. Further, it is not until adolescence that young people experience shame about a particular characteristic of self or shame about a characteristic shared by others with the same cultural identity (Harter, 1999). However, research with young children highlights that it is not necessary to understand the concept of shame to experience the affect that accompanies it. Shame may be particularly relevant for individuals who believe they do not meet cultural expectations of competency,



as may be the case for someone with an intellectual disability. For example, a young person with an intellectual disability may experience shame at being unable to read.

### **1.7.6 Concluding thoughts**

The developmental literature on the self is extensive. An attempt was made to pick out developing abilities in relation to the self that would seem theoretically most pertinent to perceiving the self as different or socially devalued. It would not be possible to provide a comprehensive account of the underpinning theory and research relating to the developmental stages described. What becomes clear is that the development of children's social cognitive abilities is a complex and gradual transactional process, involving children's cognitive abilities, their social environment and the characteristics they bring to different social situations. The many existing models concerning the development of self are based on normative samples and focus on the life experiences of people without disabilities. As a result, it is difficult to piece together a detailed picture of how perceptions of difference and the emotions accompanying them may emerge for children with intellectual disabilities. The literature does, however, describe key abilities and 'milestones' that may be implicated.

In relation to this thesis, a key question concerns the ability to become aware that they belong to a social category described by Down syndrome or intellectual disability. Children tend to use concrete and observable features when describing the self and others (Harter, 1999; Livesly and Bromley, 1973). However, while children may notice physical differences of their peers with disabilities, whether they formulate a social category according to these differences may depend on the frequency with which they see people with Down syndrome and the amount of information they are provided about it by those close to them.

The ability to form higher-order trait descriptions of self (for example, stupid or different from everyone else) appears to emerge as their abilities to integrate previously separate self-perceptions increases around the ages of 8 to 11 years old. The ability to integrate self-perceptions also means that children can construct a sense of global self-worth. However, it is emphasised that although children may not be able to articulate a global sense of self-worth, behavioural displays indicate they can experience feelings of low-self worth (Harter, 1999).

The ability to compare the self to others, at around 8 to 11 years old would also appear to be critical to perceiving the self as different. For example, comparing one's performance to school peers or siblings at home may inform a child with an intellectual disability of their difference.

Finally, the ability to appreciate others' perspectives can contribute to children's awareness that they are being treated in a stigmatised fashion and being treated different as persons. Furthermore, sensitivity to others' judgements and evaluations may lead to feelings of shame, and an awareness that one cannot live up to expected standards. Once again, the research suggests that children's sensitivity to how they are viewed by others might be evident before they are able to articulate their feelings. This begs the question as to whether the existing literature with people who have intellectual disabilities proves sensitive to these complex processes relating to children's growing awareness of their social identities.

## **Chapter 2: Systematic review**

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### **2.1 Aim**

This review draws together the existing literature on children and young people with intellectual disabilities, to examine whether there is evidence to suggest if and when they develop knowledge of their disability or awareness of stigma. The studies will be described and critically examined.

### **2.2 Introduction**

In the preceding chapter, previous research examining adults with intellectual disabilities' awareness of their disability and the stigma associated with it was reviewed. The findings of these studies were contradictory and suggested that while some adults with intellectual disabilities were aware of their disability and sensitive to stigmatised treatment, others appear to have been successfully 'sheltered' by significant others (Jahoda et al., 1988; Todd and Shearn, 1997). The present review aimed to identify studies investigating young people with intellectual disabilities' perceptions of their disability and the social stigma attached to it. A small body of literature was found using an electronic search of Medline and PsycINFO, a hand-search of key journals and by examination of the reference sections of relevant papers. The search strategy is detailed below. Both quantitative and qualitative research was found and these two types of research will be reviewed separately, beginning with the quantitative studies. An overall discussion of both sets of research will be provided at the end.

### **2.3 Method**

#### **2.3.1 Search strategy**

Publications from peer reviewed journals were identified by carrying out an electronic search of research databases and a hand search of key journals.

#### **2.3.2 Electronic search of databases**

An electronic search of the following databases was carried out: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) and PsychINFO. Search

results were limited to those published in English, and in peer reviewed journals from 1990 to June 2013, when the search was conducted. The electronic search comprised two components, a text word search and a search of index terms, as defined by the respective database. Advice was sought from a Glasgow University librarian who is an expert in carrying out reviews of research literature.

The search strategy used in PsycINFO, accessed via EBSCO, was as follows:

(TX "social\* stigma\*" or stigma or stigmati\* or social\* identi\* or disab\* identi\* or shame\* or prejudice\* or self?concept\* or negative attitude\* or social?perception\* or self?perception\* or self?awareness or social comparison\* or bully\* or social?exclu\*) OR (DE social identity or group identity or self perception or Social Perception or social cognition or stereotyped attitudes or stigma or prejudice or social discrimination or shame or embarrassment or social comparison or bullying)

AND

(TX children or child or childhood or adolescen\* or pre-adolescenc\* or juvenile\* or youth or teen\* or pre-school or school age\* or pupil\* or student\*) OR (DE adolescent development or adolescent psychopathology or child psychology or developmental psychology or child psychopathology or preschool students or childhood development)

AND

(TX intellectual\* disab\* or intellectual\* disorder\* or intellectual\* handicap\* or intellectual\* impair\* or intellectual\* deficien\* or intellectual\* subnorm\* or learning disab\* or learning disorder\* learning impair\* or learning difficult\* or developmental\* disab\* or developmental\* disorder\* or developmental\* handicap\* or developmental\* impair\* or developmental\* delay\* or mental\* disab\* or mental\* handicap\* or mental\* impair\* or mental\* deficien\* or mental\* subnorm\* or mental\* retard\*) OR (DE intellectual development disorder or "Intellectual Development Disorder (Attitudes Toward)" or developmental disabilities or fragile x syndrome or prader willi syndrome or rett syndrome or williams syndrome)

**The search strategy used in Medline, accessed via Ovid, was as follows:**

(intellectual\* disab\* or intellectual\* disorder\* or intellectual\* handicap\* or intellectual\* impair\* or intellectual\* deficien\* or intellectual\* subnorm\* or learning disab\* or learning

disorder\* learning impair\* or learning difficult\* or developmental\* disab\* or developmental\* disorder\* or developmental\* handicap\* or developmental\* impair\* or developmental\* delay\* or mental\* disab\* or mental\* handicap\* or mental\* impair\* or mental\* deficien\* or mental\* subnorm\* or mental\* retard\* or (education\* adj3 subnorm\*).tw. OR (exp Mental Retardation/ or exp Mental Retardation, X-linked/ or exp "Education of Mentally Retarded"/ or exp Developmental Disabilities/ or exp Mentally Disabled Persons/)

AND

(children or child or childhood or adolescen\* or pre-adolesc\* or juvenile\* or youth or teen\* or pre-school or school age\*).tw. OR (exp Child/ or exp Adolescent/ or exp Child, preschool/)

AND

((social\* adj3 stigma\*) or stigma or stigmati\* or social\* identi\* or disab\* identi\* or shame\* or prejudice\* or self?concept\* or negative attitude\* or social?perception\* or self?perception\* or self?awareness or social comparison\* or bully\* or social?exclu\*).tw. OR (exp Social Identification/ or exp Stereotyping/ or exp Social Stigma/ or Self Concept/ or exp Prejudice/ or exp Shame/ or social perception/ or bullying/ or social?marginalization/)

### **2.3.3 Hand search of articles and key journals**

The reference lists of relevant articles identified in the electronic database were also searched. In addition, a search of the contents pages of several key journals was conducted:

American Journal on Intellectual and Developmental Disabilities (2003-2013)

Journal of Intellectual Disabilities (2003-2013)

Journal of Intellectual Disability Research (2003-2013)

International Journal of Developmental Disabilities (2003-2013)

Journal of Applied Research in Intellectual Disabilities (2003-2013)

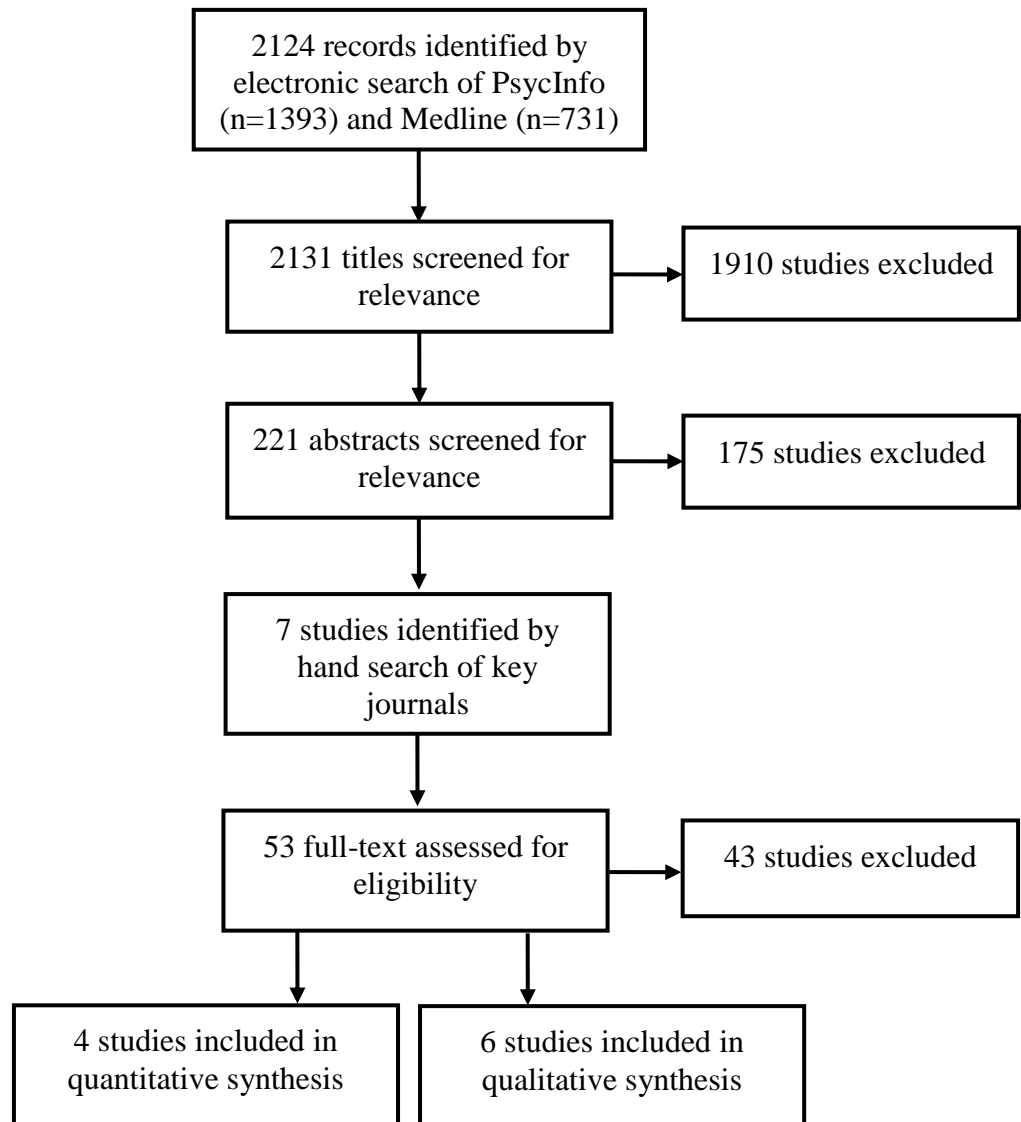
### **2.3.4 Inclusion and Exclusion criteria**

Studies were included in the review if they examined the awareness, knowledge or understanding of disability in children with intellectual disabilities and/or any aspect of the social stigma associated with it. Studies were included if the sample participants were aged up to 24 years old. This age range was chosen because it was thought to include early adulthood, and encompass the impact of major stages of transition in young people's lives, such as, moving from school to college or the work place. All the studies included were published in peer-reviewed journals and written in English. Dissertation abstracts, book chapters and conference proceedings were excluded from the review. Finally, only research carried out in Western countries was included as attitudes towards disability and the stigmatised treatment people receive are inextricably bound to culture.

## **2.4 Results**

### **2.4.1 Article selection**

Having run the search strategy in each database, the resultant citation titles were examined for potential relevance to the research question. The abstracts of those papers deemed potentially relevant were then read. Those articles whose abstract appeared to confirm their relevance were read in full. The articles retained at this stage comprised the final set of papers to be included in the review. Papers were sorted into two sets, those using quantitative methods and those using qualitative methods, so that they could be reviewed separately. Figure 1 details the process of article selection.



**Figure 1: Flow diagram of study selection process**

## **2.5 Part 1: Quantitative studies**

### **2.5.1 Article quality and rating criteria for quantitative studies**

In order to assess the quality of the articles a grading system was devised. The quality criteria were developed with reference to established guidelines (SIGN, 2003) and by reflecting on what study features were salient to the question posed by present review. In summary, the criteria identified were:

- 1) The clarity of the research questions and study aims
- 2) The suitability of the research design to the research question

- 3) The size of sample
- 4) The appropriateness of the measures for people with intellectual disabilities
- 5) Whether intellectual disability was measured by a validated assessment or collected from school records

Of fundamental importance was that researchers had clearly stated the aims of their study with reference to previous research and theory. Since children with intellectual disability will have some level of intellectual impairment, the most efficacious design would attempt to control for both the effects of intellectual ability and chronological age by including two matched comparison groups of young people with no disability. The strongest studies would also have a sample size that was informed by a power calculation to ensure that type II errors are avoided. People with intellectual disabilities have particular communication needs that mean research methods have to be accessible to them in order to collect meaningful data. The most reliable and valid measures would have been normed for young people with intellectual disabilities. However, very few measures have been normed with the intellectual disability population. Therefore, measures were considered to be strong if they had been validated on a non-disabled child population and adapted for use with young people with intellectual disabilities. Measures constructed with young people with intellectual disabilities in mind, and piloted on them, would also constitute a strong measure. Finally, the strongest studies would include details about the intellectual functioning of the participants using a validated tool or school records.

Each identified study was assessed according to the criteria described above using a checklist. However, rather than using the criteria to assign each paper a quality score, a quality grading system was developed. This was because not every criterion was considered of equal value. For example, if a paper's author(s) did not use measures that were suitable for use with young people with intellectual disabilities, the study was regarded as very poor, regardless of how it fared on the remaining criteria. The quality grades developed are described below, beginning with the highest level of quality, 1a.

*Level 1a (Excellent):* The research question and aims of the study were clearly stated; the study design incorporated a group of young people with intellectual disabilities and two comparison groups of young people with no disabilities matched for developmental level



and chronological age; the sample size was based on a power calculation; a standardised measure was used demonstrated to be valid and reliable for use with people with intellectual disabilities; intellectual disability was measured using a validated instrument.

*Level Ib (Good):* The research question and aims of the study were clearly stated; the study design incorporated a group of young people with intellectual disabilities and one comparison group of young people with no disabilities; a convenience sample was obtained; a standardised measure adapted for use with young people with intellectual disabilities was used or a measure developed for the study taking into consideration the needs of people with intellectual disability; intellectual disability was measured using a validated instrument.

*Level Ic (Adequate):* The research question and aims of the study were clearly stated; no comparison group was used; a convenience sample was obtained; a standardised measure was adapted for use with young people with intellectual disabilities or a measure developed for study taking into consideration the needs of people with intellectual disability; intellectual disability was measured using a validated instrument.

*Level IIa (Poor):* The research question and aims of the study were clearly stated; no comparison group was used; a convenience sample was obtained; a standardised measure was adapted for use with young people with intellectual disabilities or a measure developed for the study taking into consideration the needs of people with intellectual disability; intellectual disability not measured.

*Level III (Very poor):* The research question and aims of the study were clearly stated; no comparison groups; convenience sample; suitability of measures for people with intellectual disabilities questionable; intellectual disability not measured.

*Level IIII (Extremely poor):* The research question and aims of the study not clearly stated; no comparison groups; small convenience sample; suitability of the measures for people with intellectual disabilities is questionable; intellectual disability not measured.

## **2.5.2 Results of study quality evaluation**

The quality of the papers was assessed using the above criteria above by the first author. Each study was given an overall quality grade that ranged from level I to level III. Studies

that were graded below level I would have been regarded below a suitable standard and omitted from the review. However, none of the studies fell into this category. A second independent rater also carried out quality assessment using the quality criteria and the inter-rater agreement was determined. The level of agreement was 100%.

The review included four studies. Table 1 shows how each study fared according to the quality criteria. Four studies received an adequate quality grading, while one was graded as good.

**Table 1: Quality grading of quantitative studies**

Study	Quality grade
Szivos (1991)	Ic
Szivos-Bach (1993)	Ic
Cooney et al. (2006)	Ic
Crabtree and Rutland : study 1 (2001)	Ib
Crabtree and Rutland : study 2 (2001)	Ic

### 2.5.3 Data extraction for quantitative studies

Key information was extracted from the studies under the following headings: study aims and design, characteristics of the sample, the methods used, the main findings of the study and methodological limitations. The four quantitative studies are summarised in tables 2-5.

**Table 2: Szivos (1991) Social comparisons with siblings made by adolescents with a learning difficulty**

Aims and design	Sample	Measures/method	Main findings	Limitations
<p>To measure social comparisons with siblings made by adolescents with IDs</p> <p>Investigate relationship between social comparisons and self-esteem</p> <p>Investigate how participants cope with the potentially negative outcomes of social comparisons they make</p>	<p>N= 50 (20 female and 30 male) aged 16-21 years old</p> <p>Mild intellectual disability</p> <p>All attended Further Education courses attached to mainstream FE colleges</p> <p>All had previously attended special schools</p>	<p>Interview format</p> <p>British Picture Vocabulary Test (BPVT: measure of IQ)</p> <p>The Social Comparisons Scale (developed for study) composed of self-esteem and rated esteem of chosen sibling. Three scores derived: Self-esteem; Sibling score; Discrepancy score (self score minus sibling score).</p> <p>The Stigma Scale (developed for study)</p> <p>Self esteem score and stigma score later combined for analysis because highly correlated</p>	<p>BPVT scores showed no relationship with any variables (mean= 50.96; mean MA= 9 years 4 months).</p> <p>Older, same sex siblings were chosen for social comparison more often, got higher esteem scores and were rated as superior to participants more than younger opposite sex siblings, who were chosen least often, received lower scores and were seen as inferior to participants.</p> <p>Findings interpreted in terms of ways in which social comparisons can be used to serve self-esteem (defensive use of social comparisons). It is suggested that it is acceptable to look up to older sibling, by contrast, negative outcomes of comparisons with younger sibling present a threat to self esteem and derogation used to protect self.</p> <p>Gender effect explained by drawing on gender identity development literature. Own gender valued while opposite gender derogated.</p> <p>Adolescents with younger siblings more anxious than those who compared themselves to older siblings. Participants who were most anxious were those with younger same gender siblings.</p> <p>Participants who felt most inferior to sibling also perceived most stigma.</p>	<p>No comparison group of non-disabled young people</p> <p>convenience sample</p> <p>No test-retest reliabilities for measures</p>

**Table 3: Szivos-Bach (1993) Social comparisons, stigma and mainstreaming: The self-esteem of young adults with a mild mental handicap**

Aims and design	Sample	Measures/method	Main findings	Limitations
<p>To investigate potential relationships between self-esteem, social comparisons and participants' aspirations and expectations of fulfilling them.</p>	<p>N=50 students (20 female and 30 male).</p> <p>All attended Further Education centres in England</p> <p>Aged 16-21, mean age 18 years old.</p> <p>Mild to moderate ID</p>	<p>Interview format.</p> <p>BPVT used to measure IQ</p> <p>Social comparison test (developed for study) composed of self-esteem and rated esteem of four others (friend with ID; favourite sibling, a person without ID and ideal self).</p> <p>Perception of Stigma questionnaire (developed for study).</p> <p>Aspirations and expectations of achieving them (developed for study)</p>	<p>Social comparisons: Participants rated self as similar to friend with ID and rated other person without ID as superior to self.</p> <p>Participants showed tendency to view older siblings as superior to self and younger siblings inferior. Same-sex siblings seen as superior to self and opposite-sex siblings inferior to self</p> <p>Participants with highest self-esteem had higher ideals (ideal self-score)</p> <p>Stigma: participants with highest self-esteem and highest ideals showed least awareness of stigma. Participants who perceived most stigma also perceived themselves as inferior to their comparison targets (non-disabled other, siblings and ideals).</p> <p>Aspirations-Expectations: Participants with highest rated ideal self had higher aspirations. Participants with least expectation of fulfilling aspirations felt most stigmatised.</p>	<p>Large range of IQs obtained from BPVT, Szivos-Bach notes that this may throw doubt on validity of test for population-test anxiety may have led some to score lower than actual ability, others had higher receptive vocabulary skill relative to other abilities</p> <p>Convenience sample</p> <p>No test retest reliabilities for measures</p> <p>No comparison group of individuals with no disability.</p>

**Table 4: Cooney, Jahoda, Gumley and Knott (2006) Young people with intellectual disabilities attending mainstream and segregated schooling: Perceived stigma, social comparison and future aspirations**

Aims	Sample	Measures	Main results	Limitations
Investigate the impact of school setting (mainstream vs. segregated) on perceived stigma, social comparisons with peers and future aspirations	N=60 aged 15-17 years with mild to moderate ID  28 attended mainstream school; 32 segregated school in West of Scotland	Between group comparisons (mainstream pupils with ID vs. segregated pupils with ID) on self-report measures:  Adapted Social Comparison Scale (Dagnan & Sandhu, 1999).  Modified Life in School Checklist – Junior school version (Arora, 1987).  Experience of Stigma Checklist (developed for study)  Future Aspirations Checklist (developed for study)  BPVS-r (Dunn, 1997)	Only mainstream pupils reported frequent stigmatised treatment in school, however both groups reported stigma in their local area  Both groups pupils compared themselves positively with a more disabled and a non-disabled peer  Mainstream pupils more ambitious but both groups felt equally likely would attain goals	Segregated school pupils came from more deprived areas than mainstream, however SES found to be unrelated to all dependent variables  The reliability for Social Comparison Scale was low for comparison with non-disabled peer  Many potential participants declined to take part  No comparison groups of participants with no disability  Convenience sample

**Table 5: Crabtree and Rutland (2001) Self-evaluation and social comparison amongst adolescents with learning difficulties**

Aims	Sample	Method	Main findings	Limitations
<p>Study 1: To compare self perceptions in six domains of students with moderate intellectual disabilities (MID) and students without MID and to find out if participants with and without MID differed as to the importance they placed on each of the six domains. To compare the self-worth of those with MIDs without MID.</p> <p>Study 2: To investigate the importance of social comparison in the construction of perceived self-competence amongst adolescents with MID</p>	<p>Study 1: N= 145 (69 female) students with moderate intellectual disability attending special schools. Aged 11-16 years old.</p> <p>N= 145 (72 female) students without MID attending mainstream schools. Aged 12-15 years old.</p> <p>Study 2: N= 68 pupils (24 female) with MIDs attending special schools, aged 12-16 years old. All had a brother and sister.</p>	<p>Study 1: Self-Perception Profile for Children (Harter, 1985). Measures five domains: scholastic competence, social acceptance, athletic competence, physical appearance, behavioural conduct and general global self worth.</p> <p>Study 2: SPPC (Harter, 1985).</p> <p>Between groups design; 4 groups: 1. SPPC self only 2. SPPC in relation to another student with MID before self 3. SPPC in relation to pupil in mainstream school before self 4. SPPC in relation to sibling before self.</p>	<p>Study 1: scholastic dimension did not contribute to overall self-worth of MID students while it did for non-MID students. MID students rated athletic competence as more important than non-MID students. No between group differences on global self-worth.</p> <p>Study 2: comparative context effected the self-evaluations of adolescents with MID. Self-evaluations of physical and athletic domains were lower among student in the non-MID first condition.</p>	<p>No information on participant IQ ; deemed to have moderate learning difficulties by local education authority</p> <p>Measure not validated for use with young people with intellectual disabilities, although suitable for young children</p>

## **2.5.4 Review of quantitative studies**

### **2.5.4.1 Introduction**

The four quantitative studies identified were carried out in the UK. All of the quantitative studies used Social Comparison theory (Festinger, 1954) as the theoretical basis of their investigations. The term Social Comparison was coined by Festinger (1954) to describe a process whereby individuals compare themselves to others to evaluate their own performance in an area of interest. According to Festinger (1954), the outcome of such comparisons can have a significant bearing on an individual's self-esteem. In other words, self-esteem is enhanced if the outcome of social comparison is favourable to the self and detrimental to self-esteem if one compares oneself unfavourably to others. It is also highlighted that social comparison is an active process. That is, individuals choose who to compare themselves with. Therefore, an individual may choose to compare themselves with someone thought to be 'worse off' in order to protect or augment self-esteem (downward social comparison). Whereas, comparison with someone regarded as superior (upward social comparison) is associated with low self-esteem and psychological difficulties (Allen and Gilbert, 1995).

The first section will describe the studies of Szivos (1991), Szivos-Bach (1993) and Cooney, Jahoda, Gumley and Knott (2001). These researchers examined the associations between the participants' social comparisons, their self-esteem and their perceptions of stigma. While the constructs examined in these three studies were similar, the way the researchers chose to measure them was different and it is important to weigh up the merits of the different approaches used. Therefore, methodological considerations will be discussed before drawing final conclusions from the findings of these studies.

The second section will describe two linked studies by Crabtree and Rutland (2001) who also examined the impact of social comparisons on the self-perception of pupils with intellectual disabilities using a different method. The methods used by these researchers will also be discussed and conclusions drawn. This will be followed by a short overall discussion of the results of the quantitative studies.

### **2.5.4.2 Social Comparisons and awareness of stigma**

The first three studies that will be discussed were conducted by Szivos (1991), Szivos-Bach (1993) and Cooney et al. (2006). All three studies received an adequate quality grade and the key details of these studies are shown in tables 2 -4. Szivos (1991) begins with the assertion that social comparisons with siblings are likely to have significant consequences for the construction of one's self-concept. Therefore, she examined the social comparisons that adolescents with mild-moderate intellectual disability made with their siblings, the impact these comparisons had upon their self-esteem and the ways in which young people coped with the potentially negative outcomes of these social comparisons.

Adolescents were asked to complete a measure of self-esteem that Szivos (1991) had developed for the study. In addition, young people were asked to identify a sibling they liked or felt was most similar to them and to complete the same measure in relation to the sibling they chose. Szivos (1991) then calculated a score representing how participants saw themselves in comparison to their sibling, by subtracting participants' sibling score from their self-esteem score. Participants' experiences of stigma were also examined using a scale developed by Szivos (1991) for the study.

First of all, the results indicated that the gender and age of the participants' siblings played a central role in the participants' choice of sibling. Of the young people who had more than one sibling to choose from, the majority showed a preference for a same-sex and older sibling. Older same-sex siblings were held in highest esteem and younger opposite-sex siblings the lowest. In comparison to themselves, the students saw their older same-sex siblings as superior and their younger opposite-sex siblings as inferior. Szivos (1991) interpreted these findings in terms of how social comparisons may be used to protect self-esteem. She suggested that the reason why older siblings were viewed more positively was because older siblings pose less of a threat to self-esteem, as it is socially acceptable to look up to older siblings and see them as superior. Conversely, comparisons with a younger sibling were potentially less favourable to the participants, since siblings may achieve developmental milestones ahead of the adolescent with intellectual disabilities, despite their younger age. Szivos (1991) suggested that one way of alleviating some of the distress caused by participants' awareness that they were falling behind their younger siblings was to derogate them. Szivos (1991) explained the effect of gender by reference to gender roles and identity formation. The developmental literature shows that it is common



for children to place high value on their own gender, while derogating the opposite one (Abrams, 1990).

Szivos (1991) also found a negative correlation between students' reported awareness of stigma and their self-esteem, whereby students who were most aware of stigma had the lowest self-esteem. Further, the adolescents who saw themselves as most inferior to their siblings reported feeling the most stigmatised. These findings may support the notion that comparisons within the family may be important sources of information of one's stigmatised identity and have significant consequences for self-esteem. However, it is also possible that young people who were already conscious of their stigmatised position were driven to evaluate their younger sibling negatively, in order to protect their self-esteem. In other words, the direction of causality is unclear from the study.

In a later similar study, Szivos-Bach (1993) investigated the social comparisons that young people made with peers and the relationships between the outcomes of these social comparisons and young people's perceptions of stigma, their self-esteem and perceived likelihood of achieving their aspirations. Szivos-Bach (1993) was also interested in how these variables may be related to the degree of mainstreaming experienced by the young people. The details of this study are in table 3.

Szivos-Bach (1993) asked her participants to identify four figures: a friend on the college course (also with an intellectual disability), a favoured sibling, a person without an intellectual disability and their ideal-self. Young people completed a self-esteem measure and also filled out the same measure in relation to each of the comparison figures they had chosen. The young peoples' responses indicated that they were least positive about their friend with an intellectual disability. The participants' self-esteem ratings were correlated with their ratings of a friend, suggesting they viewed themselves as similar to their friend. Participants held the identified person without an intellectual disability and their ideal-self in the highest esteem.

Consistent with the findings from her previous study, Szivos-Bach (1993) found that participants tended to think more highly of older siblings than younger ones. When comparing themselves with their siblings, participants thought older siblings were better than them and younger siblings were rated more negatively (although this latter trend did

not reach significance). In addition, a sibling's gender also appeared to influence how participants viewed them. A consistent pattern with the first study was also found for gender, with participants favouring same gender siblings.

Szivos-Bach (1993) found that the participants perceived themselves to be significantly stigmatised. Looking at responses across measures indicated that those who had the highest self-esteem and the highest ideals showed the least awareness of stigma. Further, the students who perceived the most stigma compared themselves more negatively with the non-disabled individual they identified, and their sibling and ideal-self. The scores from the stigma questionnaire were also related to the likelihood the students felt they would achieve their aspirations. Those who felt the most stigmatised also had the least expectation of fulfilling their aspirations. The aspirations measure used by Szivos-Bach (1993) included typical life goals like marriage and gaining employment.

Szivos-Bach (1993) also intended to examine the effect of degree of integration on the above variables. However, she found that it was not possible to include level of integration as an independent variable because all teaching staff reported that they supported inclusion and used every opportunity they could to promote integration for their students. Whether this was the case in reality was not established.

The third study in this section was by Cooney et al. (2006) and they took level of inclusion as the starting point for their study. These researchers investigated how mainstream and segregated schooling contexts impacted upon young people's reports of stigmatised treatment, the outcomes of their social comparisons with peers and their future aspirations. Details of this study are found in table 4. It was found that students in mainstream schools reported more stigmatised treatment in school, than those in special schooling. However, both groups of students reported experiencing comparable amounts of stigmatised treatment outside school in the local community where they lived.

Cooney et al. (2006) asked their participants to compare themselves with a peer with a more severe intellectual disability than themselves and a peer with no disability. It was found that students in both types of school compared themselves positively to both of these comparison figures. Mainstream pupils were more ambitious than those in special schooling, aspiring to more professional jobs. However, both groups of students recognised

potential difficulties they may face when pursuing their goals and were equally likely to believe they could achieve them.

#### **2.5.4.3 Methodological considerations**

Szivos-Bach (1993) and Cooney et al. (2006) found contrasting results regarding the outcomes of participants' social comparisons with peers with and without disabilities. This warrants further consideration, in particular with reference to how social comparisons were measured in these studies. To recap, Szivos-Bach (1993) found that students rated a friend with a disability lower than a person without a disability, and that they saw a person without a disability as superior to them while there was no difference between their self score and the score given to a friend with a disability. In contrast, Cooney et al. (2006) found that students compared themselves positively to another young person with and one without an intellectual disability. These differing results may be attributable to the methods used.

In the Szivos-Bach (1993) study participants rated themselves and their social comparison figures on the measure separately. These scores were subtracted from one another by the author to yield a measure of how positively or negatively participants thought they compared with the comparison figures. In addition, participants were asked to choose their own comparison figures from people they knew in real life. In contrast, in the Cooney et al. (2006) study, participants' comparison figures were described using vignettes and were not people personally known to them. Thus, the comparison figures in Szivos-Bach's study may have held greater personal relevance for the participants, thereby allowing them to respond in a more ecologically valid way. In addition, by measuring participants' views of themselves and others separately, the need to perform more complex and abstract comparisons with others was avoided. On the other hand, separating the ratings of self and others means that the participants never made direct comparisons of themselves with others as, in effect, it was the researcher that carried out the comparison. Therefore, there were downsides to both approaches used.

Szivos-Bach (1993) found that participants who perceived the most stigma were less likely to think they would achieve their aspirations. However, Cooney et al. (2006) found no relationship between participants' experience of stigma and expectation of achieving their aspirations. Again, the measurement tools used by these authors differed and may be

implicated in the contrasting findings. Szivos-Bach (1993) asked participants to rate how much they desired several standard aspirations (e.g. 'have a job') and then to rate their ability to achieve them. The discrepancy between the two scores was calculated and was regarded as an index of how much participants believed it likely that they would achieve their aspirations. Cooney et al. (2006) asked participants to think about three aspirations of their own (for example, where they wanted to live) and then to rate the likelihood of attaining their wish. The latter method may have been more valid since the aspirations were meaningful to the participants.

Stigma was also conceptualised differently in these two studies. Szivos-Bach (1993) focussed more on how much the participants identified with more abstract feelings thought to be the result of perceiving oneself to be stigmatised. For example, 'I wish I were someone different'. By contrast, Cooney et al. (2006) focussed on participants' experiences of being treated in a stigmatised manner, for example, being called names at school. Consequently, whilst Szivos-Bach (1993) was examining whether participants had internalised a stigmatised view of self, Cooney et al. were examining whether participants were aware of experiencing stigmatised treatment by others.

#### **2.5.4.4 Concluding comments**

The findings of Szivos-Bach (1991) suggest that social comparisons with siblings may have an important influence on the self-perceptions of young people with an intellectual disability. In this study, young people tended to derogate younger siblings. Szivos-Bach (1991) interpreted this finding in terms of participants' response to the threat that comparisons with younger siblings posed to their self-esteem. Consequently, the study also highlights that young people actively choose comparisons to help protect their self-esteem.

The notion that individuals seek out favourable social comparisons and avoid comparisons that are foreseen to result in an unfavourable view of self has gained substantial empirical support in literature concerning non-disabled individuals (Suls and Wheeler, 2000). In the event of threat to self-esteem, individuals have also been shown to derogate others as a means to relieve some of the psychological distress caused (Wills, 1981; Exline and Lobel, 1997).

All three of these studies also show that young people are aware of the stigma relating to their disability. Further, the findings of Cooney et al. (2006) highlight that children do not only experience stigma in school; their experiences of stigmatisation extend beyond the school gates to the community where they live. Consequently, the mainstreaming debate may be missing the point by the suggestion that children's awareness of difference is mainly the result of contact with non-disabled peers in the classroom.

#### ***2.5.4.5 Self-perception and social comparison***

Crabtree and Rutland (2001) carried out two linked studies to investigate self-perceptions of school students with and without moderate intellectual disabilities and the effects of social comparisons on students' self-perceptions. Overall these studies were deemed adequate using the quality criteria outlined in Table 1. The details of these studies are found in Table 5. In the first study, the self-perceptions of mainstream students and those with moderate intellectual disabilities who attended special schools were measured using Harter's Self-Perception Scale for children (SPPC; Harter, 1985). The SPPC contains six subscales that measure perceived competence in five domains; scholastic competence, social acceptance, athletic competence, behavioural conduct, physical appearance and global/general self-worth. In addition, participants completed a measure of how much they valued each domain.

It was found that non-disabled students had higher self-perception scores on the social acceptance and behavioural conduct scales than those with intellectual disabilities, while students with intellectual disabilities scored higher on the physical appearance subscale than their non-disabled peers. No difference was found between the two groups on global self-worth. The analyses showed that all the domains contributed towards the global self-worth score of the non-disabled students. Conversely, in the intellectually disabled group all subscales except scholastic competence predicted self-worth. Those with intellectual disabilities also placed less importance on the scholastic domain than their non-disabled peers, but placed greater value on the athletic domain than their non-disabled peers. The authors explain this pattern of findings in terms of strategies stigmatised groups may use to maintain and protect their self-esteem (Crocker and Major, 1989), i.e. downplaying one's weaknesses and emphasising one's strengths.

Crabtree and Rutland (2001) carried out a second study which only included pupils with moderate intellectual disabilities. In this study there were four conditions in which the researchers manipulated the nature of the social comparisons made by participants, to find out if this had an effect on their perceived competence in the six domains of the Self-Perception Scale for children (SPPC; Harter, 1985). All four groups of participants completed the SPPC in relation to themselves. Participants in three of the groups also rated another specified individual on the SPPC beforehand. The three target individuals were: a fellow pupil with moderate intellectual disability, a pupil from a local mainstream school without a disability and a sibling. Crabtree and Rutland (2001) reported that participants who rated a pupil without a disability before themselves showed the lowest self-ratings on the physical appearance and athletic domains of the SPPC scale. This finding suggests that comparing themselves to a non-disabled peer led pupils to view themselves more negatively in the competence domains that were important to them.

#### ***2.5.4.6 Methodological considerations***

The use of the SPPC scale (Harter, 1985) may be seen as a strength of this study in one respect but a weakness in another. The SPPC scale measures self-perceptions in relation to five domains and allows individuals' scores on each of the domains to be easily compared. It also measures global self-worth on a separate scale, since global self-worth is thought to be qualitatively distinct from the sum of individual scales (Harter, 1999). The merit of using this scale was that the researchers were able to demonstrate how the valence of self-perceptions on five domains could differ between groups of individuals, and how each domain contributed to perceived self-worth. Further, by measuring the importance individuals placed on each domain, Crabtree and Rutland (2001) were able to show how those students with and without intellectual disabilities placed value on different aspects of self. However, a weakness of such self-perception measures is that they are prescriptive and may fail to capture the nature of people's own self-perceptions. This might be a particular problem when the self-perception scale is based on a normative data, as such data may fail to capture the experience of a stigmatised group of young people like those with intellectual disabilities who might have distinct social and developmental experiences.

### **2.5.4.7 Concluding comments**

The findings of Crabtree and Rutland (2001) highlight that young people with learning disabilities may use social comparison strategically, in order to protect their self-esteem. In their second study, Crabtree and Rutland (2001) show that even the subtle manipulation of different social comparison figures can have a significant impact on the outcomes of the social comparisons made. Thus, study two demonstrates that young people with intellectual disabilities may be vulnerable to changes in the environment that lead to less favourable social comparisons, and that this may have a detrimental impact on the young people's self-perceptions.

## **2.6 Part 2: Qualitative studies**

Nine qualitative studies were identified. These were all conducted in the UK. Qualitative researchers have investigated individuals' awareness of a stigmatised identity and their understanding of disability. Several methods have been used to achieve these goals. Todd (2000) used an ethnographic method in a school setting and collected data from pupils and school staff. This study will be described first. Three studies by Norwich (1997), Norwich and Kelly (2004), Kelly and Norwich (2004) utilised a variety of interview techniques to investigate school pupils' awareness of intellectual disability, the devalued status of intellectual disability and discriminatory treatment. They conducted a content analysis of the resultant interview data. The studies by Norwich (1997), Norwich and Kelly (2004), Kelly and Norwich (2004) will be dealt with second. Cunningham, Glenn and Fitzpatrick (2000) and Cunningham and Glenn (2004) reported findings from a large project looking at the awareness young persons with Down syndrome had of their condition using mixed methods. These researchers examined the relationship between parents' decisions to tell their offspring about Down syndrome and their child's awareness of their condition.

### **2.6.1 Evaluating the quality of qualitative studies**

There has been a long standing debate about how best to assess the quality of qualitative data (Holloway and Wheeler, 1996; Perakyla, 1997). Consequently, there are a number of appraisal checklists in the literature. However, each has its problems and none are both thorough and practical. Walsh and Downe (2006) attempted to formulate a workable framework by mapping together and synthesising eight checklists already in existence. In

order to assess the quality of the qualitative data in the present review, their checklist was used. The checklist was used to guide a discussion of the quality of the studies, rather than to arrive at a definitive decision as to whether each study should be labelled 'poor', 'adequate' or 'good'. Walsh and Downe's (2006) framework outlines essential criteria covering the following stages: scope and purpose, design, sampling strategy, analysis, interpretation, reflexivity, ethical dimensions, and relevance and transferability (see table 6 below for a full list of the criteria). Each study was examined to determine if it met the criteria. Papers were also examined by a second independent reviewer and any disagreements were resolved through discussion.



**Table 6: Quality criteria for qualitative studies (based on Walsh and Downe, 2006)**

Stage	Essential criteria
Scope and purpose	<ul style="list-style-type: none"> <li>▪ Clear statement of focus for research</li> <li>▪ Rationale for research</li> <li>▪ Questions/aims/purpose</li> <li>▪ Study thoroughly contextualised by existing literature</li> </ul>
Design	<ul style="list-style-type: none"> <li>▪ Method/ design apparent</li> <li>▪ Above consistent with research intent</li> <li>▪ Rational given for method</li> <li>▪ Data collection strategy apparent</li> <li>▪ Data collection strategy appropriate</li> </ul>
Sampling strategy	<ul style="list-style-type: none"> <li>▪ Sample and sampling method explained</li> <li>▪ Above justified</li> <li>▪ Above appropriate</li> </ul>
Analysis	<ul style="list-style-type: none"> <li>▪ Analytic approach explained</li> <li>▪ Above appropriate</li> <li>▪ More than one researcher involved if appropriate</li> <li>▪ Participant involvement in analysis</li> <li>▪ Evidence of data saturation/ discussion or rationale if did not</li> </ul>
Interpretation	<ul style="list-style-type: none"> <li>▪ Context described</li> <li>▪ Context taken account of in interpretation</li> <li>▪ Clear audit trail (sufficient so others can follow decision trail)</li> <li>▪ Data used to support interpretation</li> </ul>
Reflexivity	<ul style="list-style-type: none"> <li>▪ Researcher reflexivity demonstrated</li> </ul>
Ethical dimensions	<ul style="list-style-type: none"> <li>▪ Ethical approval granted</li> <li>▪ Documentation of how consent was managed</li> <li>▪ Documentation of how confidentiality and anonymity were managed</li> </ul>
Relevance and transferability	<ul style="list-style-type: none"> <li>▪ Relevance and transferability evident</li> <li>▪ Links to theories and literature</li> <li>▪ Limitations/ weaknesses of study outlined</li> <li>▪ Outlines further direction for investigation</li> </ul>

## 2.6.2 Reflections on the quality of studies found

All of the study authors described the scope and purpose of their research well, including the focus, rationale and aims. Moreover, it was clear how all of the studies related to previous work in the field.

In the studies reviewed, the methods and designs were described that were appropriate for their purpose. The degree of rationale provided for the qualitative method chosen however varied. Todd (2000) gives a thorough account of the appropriateness of the method chosen. The remaining studies give a little attention as to why they chose semi-structured interviews as their method of data collection. Given the participants' expressive and receptive communication difficulties, it is surprising that no consideration was given to the potential drawbacks to using methods that rely on verbal report. The process of data collection was explicit in all the studies. Kelly and Norwich (2004) and Norwich (1997) both utilised various unique strategies for eliciting responses from their participants during interviews and these methods are well described.

The sample and sampling strategy was explained in all the studies, although they varied in the amount of detail provided. Todd (2000) provided a thorough description of the sampling strategy used. The participants in Cunningham et al. (2000) and Cunningham and Glenn (2004) were recruited from a large cohort of families that had taken part in previous research with them.

All the authors explained the general process of the analyses they carried out. The majority of studies used content analysis, although this was not always made explicit. Todd (2000) used an ethnographic approach, although the exact method of analysis was not specified. In Cunningham and Glenn (2004), Norwich and Kelly (2004) and Kelly and Norwich (2004) more than one researcher was involved in the analysis. None of the researchers involved participants in reviewing their data, nor had they discussed having reached the saturation point in their data analysis.

Study contexts were described broadly in terms of current social policy. However, only Todd (2000) dealt with the immediate context of the study in detail. Similarly, Todd (2000) was the only author to address reflexivity in the interpretation of data. All of the studies used interview data to support their interpretations but none provided enough information to allow the reader insight into the processes that guided their interpretations.

Ethical dimensions were generally covered in most studies including, how approval was sought and granted, consent obtained and reference was made to both confidentiality and anonymity.

Finally, the relevance and transferability of the research studies was evident and research findings were discussed in relation to previous literature and theory in all studies. The strengths of studies were made explicit but acknowledgment of the limitations was less forthcoming and not provided by Kelly and Norwich (2004) or Norwich and Kelly (2004). In addition, avenues for further investigation were not considered by Kelly and Norwich (2004) or Norwich and Kelly (2004), although Norwich (1997) addressed this issue to a limited extent.

### **2.6.3 Data extraction for qualitative studies**

Key details of the nine qualitative studies that were identified are summarised in tables 7 to 12.

**Table 7: Todd (2000) Working in the public and private domains: Staff management of community activities for and the identities of people with intellectual disability**

Aims	Sample	Method	Main findings	Limitations
To examine the impact of stigma on people with intellectual disability's participation in community and role that care staff play.	<p>Special school for children with severe intellectual disability</p> <p>Data drawn mainly from an Outreach Unit of the school. The purpose of the Unit was to prepare children for post-school life. There were 21 students in the Unit aged around the age of 16 years old. Most were ambulatory and had good self-help and communication skills</p>	Ethnography; fieldwork took place over 2-year period. Researcher joined various activities within the school and trips into the community	<p>Themes identified:</p> <p>Staff perspective Stigma: a pervasive, limiting and daunting influence. This theme revolved around staff's acute sensitivity to stigma surrounding their school and the students</p> <p>Insulated adventure: staff activity in community settings. This theme described how school staff felt responsibility for managing the students' interactions in the community and that they felt it was an awkward experience, and threatening place for the students.</p> <p>Student perspective: The students appeared to be unaware of the stigma that staff described</p> <p>Insulated perspectives: staff management of information. This theme described how staff carefully controlled the information that reached students about their disability and insulated them from an awareness of both their disability and the stigma attached to it.</p>	<p>Verbally based method</p> <p>No data on the IQ of participants</p>

**Table 8: Norwich (1997) Exploring the perspectives of adolescents with moderate learning difficulties on their special schooling and themselves: Stigma and self-perceptions**

Aims	Sample	Method	Main findings	Limitations
<p>To explore pupils' views on special schooling and integration</p> <p>Investigate whether pupils experience a tension in views of schooling in relation to stigma</p>	<p>19 pupils attending a moderate intellectual disability special school in London (7 girls); aged 13-15 years old.</p> <p>Varied in their intellectual functioning, many had additional needs</p>	<p>Semi-structured interviews</p> <p>Pupils were asked about own views of schooling and what they thought the views of a set of other people were. Specifically, a known peer at their school, people in general at their school, a known peer at mainstream school, people in general at mainstream school, their parents and siblings. Pupils were also asked about the purpose of special school and the advantages and disadvantages of going there.</p> <p>Pupils self-perceptions were elicited using two methods: (1) Pupils were asked to say seven things about themselves (2) Pupils were asked to say how they were similar to and different from a set of specified others: a liked peer at school, a disliked peer at school, two people from mainstream school and their siblings/ cousins at home.</p> <p>Finally, pupils were asked about their past selves and present selves and possible future selves.</p>	<p>Pupils expressed mixed personal views about going to special school; positive views included enjoying subjects learnt about, while negative views included comments about being teased by outsiders.</p> <p>Pupils thought their peer would hold more negative views about going to special school; these included references to school being a 'handicapped' or 'dumb' school, being shameful to come to school.</p> <p>Pupils thought that secondary school pupils' would hold more negative views; these included that special school was for those who were 'thick' or 'dumb'. Spontaneous reference to their own emotional reaction to such devaluation of their schooling by secondary school pupils (anger and shame) was also noted.</p> <p>Pupils thought their parents were positive about special school, because it helped them to learn. Pupils were less certain about what their siblings thought but comments were generally positive.</p> <p>Views about role of special schools and integration: majority thought good to have special schools; majority did not favour getting support in mainstream schools, one of reasons was mainstream pupils would make fun of them.</p> <p>Self-perceptions: 7-things method elicited self-descriptions mainly about likes. References to strengths and weaknesses from both methods. Roughly balanced proportions of strengths and weaknesses elicited and mainly positive self-descriptions across both methods.</p>	<p>Verbally based method</p> <p>No data on IQ of participants</p>

**Table 9: Norwich and Kelly (2004) Pupils' views on inclusion: Moderate learning difficulties and bullying in mainstream and special schools**

Aims	Sample	Method	Main findings	Limitations
<p>To elicit the perspectives of pupils in mainstream school and special school of two age groups.</p> <p>To examine how pupils with moderate intellectual disabilities view their special provision; to examine whether these perspectives vary according to type of special educational placement, age or gender.</p>	<p>N= 101 51 mainstream pupils. 25 aged 10-11 years; 26 aged 13-14 years.</p> <p>50 special school pupils. 26 aged 10-12; 24 aged 13-14 years.</p> <p>Attempt to balance gender across sample and urban and rural settings.</p> <p>Many pupils had language and communication difficulties and other additional areas of difficulty e.g. motor impairment</p> <p>Those with additional difficulties alongside moderate intellectual disabilities tended to be in special schools</p> <p>Mild to moderate general learning difficulties</p> <p>All held Statements of Special Educational Need (SEN)</p>	<p>Semi-structured interview and open questions</p> <p>Content analysed in terms of emergent categories as well as in relation to research questions</p> <p>Semi-structured interviews about special schooling and self-perceptions. Personal construct theory (Kelly, 1955) was drawn on for questioning about self-perceptions.</p>	<p>Majority of pupils expressed mainly positive feelings about their school and teachers, while some reported mixed views and a minority expressed negative views. The majority also preferred their current school to any other.</p> <p>Mainstream pupils were positive about special schools, whereas special school pupils were less positive about mainstream schools.</p> <p>Emergent theme bullying: 83% of sample had experienced some form of bullying – physical, verbal (name calling, labelling), teasing (similar to verbal but presented as fun or humorous) and mix of the three forms. Mixture experienced by 68%. No differences between schools, gender or age.</p> <p>Feelings about bullying: most reported mixed negative response (upset, hurt, withdrawn) and neutral response (ignoring it, not being bothered, keeping calm or telling teacher).</p> <p>Source of bullying: 52% reported bullying by pupils in own school. Pupils in mainstream and special schools reported bullying from other mainstream schools. Special school pupils reported more bullying from pupils at mainstream schools than those in a mainstream school. Pupils in special schools reported more bullying from neighbours and peers outside school than mainstream pupils.</p>	<p>IQ not measured</p> <p>Interview method limits findings to those able to express views</p>

**Table 10: Kelly and Norwich (2004) Pupils' perceptions of self and labels: Moderate learning difficulties in mainstream and special schools**

Aims	Sample	Method	Main findings	Limitations
<p>To investigate the balance between positive, negative and mixed self-perceptions</p> <p>To examine pupils' awareness and views of the labels and terms used by others to refer to them.</p> <p>To explore potential differences according to school, gender age group.</p> <p>To examine the potential tension in pupils' perspectives on their school between getting support they need but doing so at a stigmatised establishment.</p>	<p>N= 101 51 mainstream pupils. 25 aged 10-11 years; 26 aged 13-14 years.</p> <p>50 special school pupils. 26 aged 10-12; 24 aged 13-14 years.</p> <p>Attempt to balance gender across sample and urban and rural settings.</p> <p>Many pupils had language and communication difficulties and other additional areas of difficulty e.g. motor impairment</p> <p>Those with additional difficulties alongside moderate intellectual disabilities tended to be in special schools</p> <p>All held Statements of Special Educational Need (SEN).</p>	<p>Semi-structured in-depth interview</p> <p>Self-perceptions were elicited using a technique based on Personal Construct Theory (Kelly, 1955). Pupils were asked to identify similarities and differences between themselves and key others (siblings, relatives and peers at school).</p> <p>Self-perceptions were also elicited by asking pupils about how they have changed over time and how they would describe themselves to others.</p> <p>In addition, to explore pupils' views on labels and labeling, they were asked how parents/ carers, teachers and others would describe them and how they felt about such terms.</p> <p>Pupils were also read aloud a list of labels and asked if they had heard, if anyone had used it to describe them, would they use it to describe themselves and how they felt about it. The terms included: has help, learning difficulty, learning disability, special educational needs, special needs, disability, slow, spastic, stupid, spas, abnormal, retarded, backward. Handicapped and thick.</p>	<p>Self perceptions: Over 90% aware of own learning difficulties. 23% expressed that they were 'not bothered'; 44% expressed negative feelings about having learning difficulties (being upset, feeling hurt or sad, being lonely, feeling frustration and anger). 33 % expressed mixed views.</p> <p>Self perceptions of general non-academic characteristics: both mainstream and special school pupils had mainly positive and mixed self-perceptions.</p> <p>Self-perceptions of educational and academic abilities: mainstream pupils mostly mixed self-perceptions, special school pupils mostly positive self-perceptions.</p> <p>Perceptions of others' views of self in terms of general characteristics: mainly mixture of positive and negative.</p> <p>Perceptions of others' views of self in terms of educational abilities: gender difference for mainstream but not special school pupils. Mainstream boys views mainly mixed and negative. Mainstream girls mainly positive. Special school boys and girls views were mainly positive.</p> <p>Responses to labels: Older and formal terms often not recognised. Everyday terms e.g. 'thick' and 'stupid' more recognised and evaluated negatively.</p>	<p>IQ not measured</p> <p>Verbally based measures</p>

**Table 11: Cunningham, Glenn and Fitzpatrick (2000) Parents telling their offspring about Down syndrome and disability**

Aims	Sample	Method	Main findings	Limitations
<p>To explore the role that parents play in fostering their offspring's understanding of Down syndrome and disability</p> <p>Explore relationships between parental telling, child awareness of DS and developmental level</p>	<p>N= 77 young people with DS (32 female) aged 17-24 years old and their parents (Manchester DS cohort)</p>	<p>Parent interview: Parents were asked if (and how) they had told their offspring about DS, and if they thought offspring were aware or not.</p> <p>Young people with DS interview: Young people asked about self and awareness of DS.</p> <p>Young person photograph task: Young person asked to sort photographs of unfamiliar young people with DS and then place own photograph on one the two piles. Task used to determine recognition of DS in others and self-identification with DS.</p> <p>Based on above measures, young people were categorised as having awareness of DS or no awareness. Emotional reactions also noted.</p> <p>BPVS-II used to determine approximate cognitive level</p>	<p>Majority parents reported they were open about DS; roughly half had purposefully told about DS while other half had not. Those who had told and believed their child to have understood had children with a higher verbal mental age than those who had not told. The reason given by many parents for not telling was that they thought they would not understand.</p> <p>Young person's awareness: 45 young people were considered aware of DS based on interviews and photograph task, the remaining were not.</p> <p>Using logistic regression it was found that verbal mental age was the main predicting factor for awareness of DS, parental telling added little.</p>	<p>Parental telling based on recollection</p> <p>Verbal ability required to participate in interview and photograph task</p> <p>Single time point design, no comparison or control group</p>



**Table 12: Cunningham and Glenn (2004) Self-awareness in young adults with Down syndrome: I. Awareness of Down syndrome and disability**

Aims	Sample	Method	Main findings	Limitations
To investigate awareness of Down syndrome (DS) and disability in young people with Down syndrome.	77 young adults with DS and parents (45 male; 32 female)  (Manchester Down Syndrome cohort)  Young people aged 17-24	Interview with young person: BPVS-II first (measure of developmental level)  Semi-structured interview developed for study: Describe self and life; friends, social comparisons; future aspirations; knowledge of DS and disability  Photograph sorting task used to assess awareness of DS (asked to sort 16 photographs according to 'DS', 'faces that look the same' or 'those that look like you'.  Self-evaluation scales (Harter, 1985; Joseph 1979)  Leiter-R Brief IQ battery (Roid and Miller, 1997): non-verbal MA  Parent interview: what they felt their child understood about DS/ disability; how they reacted to such knowledge; if and how they had told them and siblings.	Awareness of DS or disability: Photograph task: higher VMA and NVMA able to sort photographs according to DS  VMA and NVMA were significantly associated with levels of awareness across all measures; awareness not indicated for those below 5 years VMA  Parental telling associated with awareness, but his accounted for by VMA (see Cunningham et al., 2000).  Self-evaluations: all high self-esteem (see Glenn and Cunningham, 2004).  Application of DS/ disability to self: in photograph task not all who were aware placed self-photograph in DS pile, range of spontaneous responses  Reactions to awareness of DS: 18 neutral, 2 positive, 10 negative, 9 mixed; higher VMA mixed group  Awareness of stigma: 19 mixed/negative above, 12 showed awareness of stigma.  Conceptions of DS: reflected explanations of parents, higher VMA most insightful comments. Parental explanation fitted developmental level (Cunningham and Glenn, 2000)  Social comparisons: downward and lateral comparisons; age appropriate aspirations	Interview method with participant group: difficulties of drawing conclusions from topics participants did not discuss

## 2.6.4 Review of qualitative studies

### 2.6.4.1 *A hidden identity: Life in a special school*

Todd's (2000) ethnographic study investigated the impact of stigma on young people with intellectual disabilities who attended a special school, and the role played by care staff in managing the social lives and identities of the young people. Key details of this study are shown in Table 7. The young people who took part in the study were undergoing a period of transition, whereby their teachers were preparing them for adult life beyond school by spending more time with them in the wider community. One of the main themes that Todd (2000) identified was the pervasiveness of the stigma attached to the special school and its students. Staff were acutely conscious of the stigma attached to the school and the stigmatised reactions of the public when they and the students ventured out into the community. The public were viewed as intolerant of the socially inappropriate behaviour the students sometimes displayed and this resulted in significant feelings of apprehension for staff as they felt responsibility for managing these embarrassing situations. Staff also appeared to feel as if they were being watched and judged by the public when school groups were in the community. Overall, staff felt considerable strain when managing these school outings.

Todd (2000) subsequently presented his analysis of data collected on students' perspectives of the world they occupy, which starkly contrasted with the accounts given by staff. Todd (2000) observed that students were not aware of the 'stigma potential' of their disability or their status as 'special school students' held by society. Further, while some students did acknowledge that their school was for young people with an intellectual disability, they did not appear to believe that the term applied to them personally (Todd, 2000). For many of the students, this was because they equated intellectual disability with physical or sensory impairments which did not have themselves. For Todd (2000), it seemed surprising that despite living in a world saturated with stigmatised views of them, the young people had not acquired an understanding of themselves in this way.

Todd (2000) thought that an explanation for the students' apparent obliviousness lay with the way school staff engaged in a careful control of information, thereby sheltering students from such knowledge. For instance, staff were careful not to use terms associated with disability within hearing distance of the students. Staff's comments suggested that they felt a duty to hide information from students so that their parents could handle the

issue how they wished. Further, Todd (2000) observed how staff engaged in a dialogue which reinforced the students' beliefs in a 'typical identity'. Students often discussed their future and held aspirations regarding a career, getting married and having a family, just the same as any young person their age. Despite staff believing these aspirations to be unattainable for the students, the staff participated in conversations as if these 'fictional identities' were real and in doing so validated students views. Staff appeared to hold the view that disclosure was 'bad news' for students and as such would be distressing for them. For example, one teacher said:

'I don't know if they ever should know. I think they're pretty happy with their lives. How do you think they'd be if they knew? They'd have nothing to look forward to! As it is, they enjoy talking about their lives. I think they'd just be distressed if they knew it had no real basis' (Todd, 2000, p. 614).

Todd (2000) also noted how members of the public engaged in similar behaviours. For example, during interactions with students, people were observed to 'go along with' students' stories and directed any behaviour that made reference to their disability to others in secret.

Todd (2000) used ethnographic methods and the data were collected over a period of two years. The findings build a picture of the world through the eyes of the young people with intellectual disabilities being completely at odds with that of everyone else due to the sheltering behaviours of the people closest to them.

#### ***2.6.4.2 School pupils' views of schooling and awareness of learning needs***

Three studies by Norwich (1997), Kelly and Norwich (2004) and Norwich and Kelly (2004) will be described and their findings discussed. All three studies investigated the views of school pupils using semi-structured interview techniques. In the first of these studies, Norwich (1997) aimed to explore the special school pupils' views about their schooling and their perceptions of self. The authors also sought to find out if the pupils' views reflected a tension between the positive aspects of receiving the support they required at school and the downside of attending a stigmatised establishment.

Norwich (1997) carried out semi-structured interviews with pupils to obtain their views. Key details of this study are shown in data extraction table 8. Pupils were first asked about their school and views of special schooling. In addition, pupils were asked how several others felt about their special schooling. Finally, pupils were asked for their thoughts about the purpose and efficacy of special schools and integration.

Pupils' self-perceptions were elicited using two approaches. The aim in using these approaches was to explore children's self-perceptions on their own terms. One method was to ask the pupils to say seven things about themselves. The second approach drew on Personal Construct Theory (Kelly, 1955), and asked pupils in what ways they were similar and different to a set of other people they had identified.

The interview transcripts were content analysed. The pupils reported that they thought special school was for helping people with literacy difficulties or difficulties with learning. Moreover, the majority of pupils thought it was good to have a special school like theirs. Pupils expressed mixed feelings about special school. For example, pupils liked their teachers and subjects. However, concerns were expressed about bullying, teasing or mimicking in school, and being teased by peers outside their school. One pupil commented that attending a special school was shameful. With regards to integration, most pupils expressed little confidence in the ability of mainstream schools to provide the learning support they required and thought that mainstream pupils would make fun of them.

In addition, Norwich (1997) asked pupils about others' perspectives on special school. It was found that pupils' thought their parents saw their school positively, because it catered for their needs better than mainstream school would, and it helped them to learn. Pupils were less certain about what their siblings thought, although those who answered the question about siblings' views were generally positive and referred to the school helping them to learn. However, two pupils reported being teased by siblings about their school. The positive slant of personal, parental and sibling views stood in contrast to students' thoughts about how their class peers and mainstream school pupils viewed special school. Pupils thought their peers saw the school positively because they liked the school subjects and preferred it to mainstream school, where bullying took place. At the same time, most of the pupils thought their peers viewed the special school negatively because it was a 'handicapped' or 'dumb school', it was shameful to go there and they were teased. When asked what young people who attended mainstream secondary school thought about the

special school, pupils' comments were overwhelmingly negative. Pupils thought that mainstream secondary school pupils thought that special school was for 'thick' students, it was a 'dumb school' or 'mad school' and that those that went to special school were laughed at. A few pupils also expressed their anger at being belittled by mainstream peers. Despite these negative perceptions of others views, pupils defended their school and said they felt normal and proud to be there. Thus, despite recognising that their peers at special school and young people at mainstream school viewed their school negatively, they themselves did see positive aspects to it. This highlights that young people with intellectual disabilities do not simply absorb the views of others, but that they actively construct their own views. With regards to pupils' self-perceptions, the more open-ended 'seven things' approach elicited more self-descriptions which tended to refer to likes, curriculum strengths and positive personal qualities. When comparing themselves with others, pupils focussed on similarities and differences in physical appearance. Norwich (1997) highlight that, in both methods, positive personal qualities outweighed negative ones and there was a roughly balanced weighting between the pupils' perceived strengths and weaknesses.

Kelly and Norwich (2004) also carried out semi-structured interviews with school pupils with moderate intellectual disabilities to investigate their self-perceptions and their views on the terms and labels used to refer to them. Key details of this study are shown in Table 9. Roughly half of the pupils Kelly and Norwich (2004) interviewed attended a special school while the remaining pupils attended a mainstream school. There were two age levels within each group which reflected the stages of primary and secondary schooling.

The interview data was content analysed. Potential differences in self-perceptions between students in mainstream and special school settings, age groups and genders were explored. It was found that the majority of pupils from both school settings expressed an awareness of their intellectual disabilities. Older pupils were more likely to be aware of their difficulties than younger ones. Pupils' feelings about their intellectual disabilities were mainly negative. For example, they said they were 'hurt', 'upset' and 'angry' about them. A minority of pupils expressed a mix of neutral and negative feelings about their difficulties. Although overall only a minority of pupils tried to minimise or deny their intellectual disabilities, secondary pupils were more inclined to do so than primary pupils. There were also differences in the views expressed according to gender and age. Special school boys reported that they were less bothered than special school girls and primary school pupils in special school reported that they were less bothered than secondary special school children.

The feelings pupils expressed about their intellectual disability indicated they were aware of how they were judged by the wider community.

The importance that pupils attached to their educational abilities differed depending on the kind of school they attended. Mainstream pupils reported far more mixed self-perceptions regarding academic abilities, while positive self-perceptions in this domain were more prevalent in the special school pupils, even though they actually had significant difficulties with learning. Thus, academic self-perceptions appeared to be effected by school setting in a somewhat surprising way.

The finding that pupils were able to hold both positive and negative self-perceptions, relating to different aspects of self, highlighted the multidimensional nature of self. It may be suggested that special school pupils were able to retain more positive views of their academic abilities, despite having significant difficulties, because special school afforded these pupils more favourable social comparisons. Kelly and Norwich (2004) suggest that this finding contradicts the notion that special school pupils will have negative self-perceptions due to internalising the devalued status of their school. Instead, the social comparisons provided by the immediate social environment are more significant in influencing pupils' self-perceptions, particularly regarding their educational abilities. This has potential implications for the mainstreaming debate.

Pupils were also asked how they thought others would describe them. Most pupils thought others had mixed views of them. Many pupils also gave accounts of how others saw them in relation to educational abilities. These self-perceptions showed a significant effect of school and gender, whereby boys at mainstream school expressed mainly mixed and negative views in contrast to special school boys who were mainly positive in how they thought others viewed them.

Kelly and Norwich (2004) asked pupils whether they had heard of a range of lay and formal terms used to refer to 'learning disability', the term used in schools to refer to intellectual disability. These were; 'has help', 'learning difficulty', 'learning disability', 'special educational needs', 'special needs', 'disability', 'slow', 'spastic', 'stupid', 'spas', 'abnormal', 'retarded', 'backward', 'handicapped' and 'thick'. The terms were presented on a list and read aloud to each participant. There was large variation in the extent to which the terms and labels were known to pupils. Older and more formal terms such as, 'retarded' and

'backwards' were seldom recognised. The currently accepted formal term SEN (Special Educational Needs) was not well known either. 'Learning difficulty' and 'has help' had been heard by roughly half the sample. The labels most recognised by pupils were lay terms that tend to have negative connotations, such as 'thick' and 'stupid'.

Pupils' emotional responses to the terms were also sought. 'Has help' was seen most positively out of all the terms, although it was just as likely to receive a neutral evaluation and some pupils did perceive it negatively. 'Has help' was more positively evaluated by pupils in mainstream school than those in special school. Pupils felt negatively about the terms 'thick' and 'stupid', while the term 'learning difficulty' received both neutral and negative evaluations. When asked if they would use any of these terms to describe themselves, a minority of pupils said they would describe themselves as 'slow' or 'stupid'. A small number of pupils in mainstream school also said they would use the term 'thick' to describe themselves, but none of the special school students did. A small number of participants also described themselves as 'having help', and special school pupils were more likely than those in mainstream schools to describe themselves in this way. In comparison to their personal use of the terms, pupils were more likely to report that others used these terms to describe them. The most common terms pupils thought that others used to describe them were 'thick', 'stupid' and 'spastic'. 'Has help' was the most common neutral term that pupils reported others used to describe them. Kelly and Norwich (2004) note that the current terms in formal usage, 'SEN' and 'learning difficulty' were seldom reported as being used by pupils to describe themselves or used by others to describe them.

There were few differences in pupils' responses according to school and age group. However, those that were found are worth mentioning. Secondary school aged pupils had more negative evaluations of certain labels; 'learning disabilities', 'learning difficulties', 'disability', 'spastic' and 'backward'. Secondary pupils had also heard of more terms than primary school pupils and were more likely to report that the terms 'spas' and 'thick' were used by others to refer to them than primary school pupils.

In another paper originating from the same research project, Norwich and Kelly (2004) reported on pupils' views of their schooling provision. Key details of this study are shown in data extraction table 10. An emergent theme in this study was pupils' experiences of bullying and, due to its relevance to the present review, this section of the paper will be

described. The majority of the sample had experienced bullying and roughly half said the bullying was specifically related to their learning difficulties. Most pupils also talked about how this made them feel and the most common feelings were mixed, that is they talked about negative feelings (upset, hurt and withdrawn) and neutral ones (ignoring it, not being bothered, keeping calm or telling a teacher). Pupils attending special and mainstream schools reported that bullying had taken place in school. All pupils reported bullying from peers in other mainstream schools but those in special schools reported this more often than those in mainstream schools. Special school pupils also reported more bullying from neighbours and peers outside school than mainstream pupils.

#### ***2.6.4.3 Methods and concluding comments***

The studies by Norwich and Kelly showed that the school pupils they interviewed were aware of their disability, the learning difficulties they experienced and the negative evaluation of them by peers as a result. Pupils also reported that they had experienced stigmatised treatment as a result of being labeled intellectually disabled. The findings from these studies also suggested that school setting had an impact on how pupils saw themselves. In particular, pupils' perceptions of their academic abilities were differentially effected by school placement. While feeling negatively about their intellectual difficulties and being aware of others' negative views of their difficulties, the pupils reported having generally positive views of self. Such findings point to the complexity of self-perceptions. In one sense, pupils' self-perceptions may seem disjointed, while in another sense they highlight the active role that individuals play in interpreting and appraising their own and others views in creating their views of self. A strength of this work lies in the variety of interview techniques used and the complexities and tensions they were then able to reveal in pupils' self-perceptions. Norwich and Kelly's studies highlight the value of more idiographic approach and giving young people the opportunity to express their self-perceptions in their own terms.

#### ***2.6.4.4 Young people with Down syndrome's awareness of disability and developmental level***

Cunningham, Glenn and Fitzpatrick (2000) aimed to explore the role that parents played in their offspring's awareness of Down syndrome. Key details of this study are shown in data extraction table 11. Participants were drawn from a large cohort of young people and their families who had taken part in previous studies. In the investigation, 77 young people aged



17-24 years old and their parents took part. The young people took part in an interview, the purpose of which was to find out whether or not participants were aware of Down syndrome and/or disability and, if they were, how they felt about it. The interview was supplemented with a photograph task in which young people were asked to sort photographs of other young people of their age group into piles of those with and without Down syndrome. Young people were also asked to place a photograph of themselves in one of the resulting piles, in order to assess self-categorisation. A parent of each young person was interviewed to ascertain if they had told their child about Down syndrome and disability, why they had chosen to (or not), the explanations they had given and what they thought their child understood and felt about Down syndrome and/or disability. The data from each of these three sources was used to classify young people as either having demonstrated an awareness of Down syndrome or not. The young people also completed the British Picture Vocabulary Scale (BPVS-II; Dunn, Whetton and Burley, 1997), and this was used to provide an approximate measure of verbal mental age, an indication of their cognitive functioning (Cunningham et al., 2000).

The data collected from the interviews with parents will be described first. Many of the parents who were interviewed spontaneously revealed that they thought they operated an 'open house' in terms of discussing Down syndrome and did not avoid using the term. About half of parents said they had purposefully tried to tell their child about Down syndrome and the remaining parents had not. Cunningham et al. (2000) found that the offspring of parents who had been told about Down syndrome and were thought to understand what they had been told had higher verbal mental ages than those who had not been told. All of the young people who had been told about Down syndrome and were believed by their parents to show understanding had a verbal mental age above 5 years old.

Cunningham et al. (2000) asked parents how they approached telling their offspring about Down syndrome. Some families reported having waited until their child asked about it, while others took a more proactive approach and used available social opportunities to bring the topic up. For example, they may have pointed out people with Down syndrome on the television. The researchers also asked parents what had prompted them to tell their offspring about Down syndrome. Some families reported that the young person had drawn attention to their resemblance to someone else with Down syndrome, while others said that the young person had noticed people staring at them and had asked why this was happening. Other families said the young person had asked why they were not allowed to

do certain things that their siblings could. Finally, parents said they had told their offspring because other children or siblings had been asking about the young person's disability, prompting them to also tell the young person themselves. The explanations parents gave their children about Down syndrome tended to focus on facial features and special needs in schooling and/or health.

Like their parents, young people also took part in an interview. In addition, young people completed a photograph sorting task designed to assess their awareness of Down syndrome. Young people were categorised into those who were aware and not aware of Down syndrome dependent upon their responses in the interview, performance on the sorting task and the reports of their parents. The main finding was that the young person's verbal mental age (as measured by the BPVS-II; Dunn et al., 1997) predicted whether or not a young person demonstrated an awareness of Down syndrome (Cunningham et al. 2000).

This finding about verbal mental age led the researchers to conclude that whether or not parents chose to tell their offspring about Down syndrome was determined by their child's developmental level. That is, parents were sensitive to their child's readiness for information and this guided whether they would talk to their offspring about Down syndrome. This research adds a cognitive-developmental dimension to awareness of disability in people with intellectual disabilities. Cunningham et al. (2000) suggest that a verbal mental age of at least 5 years old appeared to be critical for an awareness of Down syndrome. This age fits with a general cognitive-developmental framework based on children's ability to understand other social categories.

Cunningham and Glenn (2004) report in more detail on the data collected from the interviews with young people. Key details of this paper are shown in data extraction table 12. During the interview, young people were asked open ended questions that encouraged them to describe themselves and their lives, and anything they would like to change. Young people were also asked about their awareness of Down syndrome and disability, using the terms used by their family (e.g. handicap, special needs, learning difficulties or disability). In addition they completed a task in which they were asked to sort photographs of other young people according to whether or not they had Down syndrome.

In the photograph sorting task, over half the sample sorted the photographs according to Down syndrome. Those who successfully completed the photograph sorting task had a

higher verbal mental age (mean verbal mental ages 7.8 and 6.8 years) than those who did not (mean verbal mental age 4.8 years; Cunningham and Glenn, 2004).

According to Cunningham and Glenn (2004) the information collected from the young person and parent interviews indicated four levels of awareness of Down syndrome or disability. These were; 'no awareness', 'simple awareness' (e.g. knew the word and could name someone with Down syndrome), 'concrete awareness' (e.g. definitely aware, used terms like Down syndrome and disability, and provided descriptions of what they meant) and 'social-relational awareness' (knew the terms and related them to effects on social life, often in comparison with others). Young people who showed the higher levels of concrete and social-relational awareness also had significantly higher verbal mental ages than those who were considered unaware of Down syndrome or disability. Those who discussed Down syndrome in terms of social relational meaning had the highest mean verbal mental age of around 9 years old (Cunningham and Glenn, 2004, p. 37).

With regards self-categorisation according to Down syndrome, it was found that not all of the young people who showed awareness of Down syndrome related it to themselves. Moreover, there was no difference in verbal mental age between the two groups. Those who did not self-identify as having Down syndrome sometimes also showed a strong emotional reaction to Down syndrome. For example, after successfully sorting photographs of others according to Down syndrome and being handed a self-portrait photograph, some of these young people were adamant that their photograph did not belong in the Down syndrome pile, or refused to place the photograph on either pile. During the task, the researchers also noted that some young people expressed negative reactions to Down syndrome by, for example, saying "ugh" to every picture of a woman with Down syndrome, or saying "not one of them" (Cunningham and Glenn, 2004, p. 348). Other young people showed an awareness of the term 'handicap', but defined it in terms of physical impairments and in this way seemed to exclude themselves from the category since they did not have such disabilities.

The interview data relating to young people who were aware of Down syndrome and applied it to themselves was further examined to explore their emotional reactions to Down syndrome. The majority of young people had no emotional response and their parents corroborated this by reporting they had never shown an emotional response. However, Cunningham and Glenn (2004) interpreted the responses of many young people as

demonstrating a negative reaction. For example, some young people appeared unwilling to discuss Down syndrome or seemed to deny it with comments such as, "I'm not Mencap, I'm British. Other young people made a realistic appraisals of Down syndrome (e.g. "It makes my heart bad and stops me [doing] something"). However, very few young people made reference to positive aspects of Down syndrome or saw it as a positive attribute. Those in the group that made realistic appraisals of Down syndrome had a significantly higher verbal mental age than the other groups. Those in this group also tended to be female, while those who had a negative reaction tended to be male. However, the researchers note that verbal mental age was confounded with gender, as females tended to have higher verbal mental ages. Thus, while the potential gender effect is interesting it was impossible for Cunningham and Glenn (2004) to separate these factors.

Cunningham and Glenn (2004) also explored young people's awareness of stigma. Many of the young people were regarded as having experienced stigma. For example, some comments reflected an awareness of stigma were that people with Down syndrome are 'not normal' or they reported being treated differently because of the condition. Again, the developmental level of all those who expressed an awareness of stigma was above 5 years old. However, in most cases, experiencing stigma did not appear to be associated with distress.

#### **2.6.4.5 Concluding comments**

The studies by Cunningham et al. (2000) and Cunningham and Glenn (2004) would also suggest that many young people are aware of disability and the attached stigma. Cunningham et al. (2000) and Cunningham and Glenn (2004) relate young people's awareness to their verbal mental age, taken to be an indicator of developmental level. It makes theoretical sense that developmental level or cognitive ability would be a strong contributory factor to one's understanding of such a social category and where one stands in relation to it. However, it may be argued that the finding that those with a higher verbal mental age demonstrated more awareness could have been an artefact of the test situation and a reflection of their greater verbal ability rather than awareness per se, since the measures all had a significant verbal component. Similarly, with regards to the finding that the parents who had told their offspring about Down syndrome had offspring who had higher verbal mental ages, it could be argued that this simply reflects the fact that those who had greater verbal skill were more able to ask their parents about it. In short, by using

the BPVS-II (Dunn et al., 1997), primarily a measure of receptive vocabulary, these researchers have confounded the ability to demonstrate an awareness of Down syndrome during interviews with verbal ability.

A strength of Cunningham and Glenn's (2004) study was the mixed methods approach and use of multiple sources of information. It is also of interest that Cunningham and Glenn (2004) observed that the photograph task prompted comments from young people that were not elicited from the interviews. Thus, pictures could be a useful way of stimulating discussion with young people regarding disability issues.

#### **2.6.4.6 Discussion of qualitative studies**

Three sets of quite different qualitative studies have been described in this review. The first ethnographic study by Todd (2000) stands out from the rest not only because of the method used and level of analysis carried out, but because the findings appear to contrast sharply with those of the other studies. Todd (2000) found that the young people in his study appeared to be completely oblivious to their disabilities and the stigma attached to them and their school. In complete contrast, the research carried out by Norwich and Kelly (2004) found that their participants not only were aware of their learning disability but also held complex ideas and views about this matter. For example, they were aware that their own views differed from those of many of their peers and others out with the school. Despite this, they could see the positive contributions their school made in their lives.

It is difficult to reach a conclusion as to why the findings of these studies are so different. However, the merits of the different approaches deserve some mention. Clearly ethnography allows for data of great quality and depth to be gathered. The methods used by Norwich (1997), Norwich and Kelly (2000) and Kelly and Norwich (2000) have shown however that by using a variety of interview techniques, the complexities and tensions that exist in self-perceptions can be revealed. Furthermore, such complexities highlight that individuals actively interpret others' views and help to shape or maintain their own sense of self.

A reoccurring theme across studies is that young people show a tendency to define intellectual disability with reference to physical impairments (Todd, 2000) or focus on the physical consequences of Down syndrome when describing it (Cunningham and Glenn

(2004). This may reflect the ease with which observable characteristics can be described and explained to others.

## 2.8 Final discussion of all studies in review

Looking across all of the studies examined in this review, it can be seen that there are three key constructs that have been investigated in relation to young people's awareness and understanding of disability and/or stigma. These are self-perceptions, self-esteem and social comparisons.

With regards to self-perception, research has centred on the question of whether disability or stigma features in young people's perceptions of self. Quantitative researchers have used standardised scales that measure predefined domains and have limited response options. By contrast, qualitative researchers have adopted an idiographic approach that is open to individual and group differences. Despite these different approaches, some tentative conclusions can be drawn from the research presented, regarding the presence of disability and stigma in the self-perceptions of young people with intellectual disabilities. With the exception of Todd (2000), the studies suggest that young people have at least some awareness of disability and stigma (Szivos, 1991; Szivos-Bach, 1993; Cooney et al. 2006; Norwich, 1997; Norwich and Kelly, 2004; Kelly and Norwich, 2004; Cunningham and Glenn, 2000, 2004). However, disability and stigma do not appear to be central to young people's self-perceptions (Crabtree and Rutland, 2001).

Researchers have also investigated the impact that young people's awareness of disability and stigma has on their self-esteem. However, the findings have been inconsistent as Szivos-Bach (1993) found that an increased awareness of stigma was associated with lower self-esteem, but other researchers have reported that young people often maintained positive views of self despite such awareness (Crabtree and Rutland, 2001).

A social comparison framework has commonly been employed to investigate young people's awareness of their disability. This is because comparisons with more able others have been considered to be an important source of information regarding one's limitations. Several studies have shown that, at least under manufactured conditions, young people with intellectual disabilities have utilised social comparisons and that such social comparisons have had a detrimental impact on their self-perceptions (Szivos, 1991; Szivos-Bach, 1993; Crabtree and Rutland, 2001). However, the findings of Cooney et al. (2006)

do not support this assertion. Social comparison research has also highlighted that people make use of social comparisons and may choose with whom to compare themselves in order to protect and enhance their self-esteem. For instance, Szivos (1991) reported that, where possible, young people showed a tendency to choose an older sibling as a comparison target. This was thought to be because such comparisons afforded the most socially acceptable and favourable result. However, when forced to compare with a younger sibling, as this was the only sibling the young person had, participants were driven to derogate them in an attempt to protect their self-esteem.

Social comparison theory has also been used in the debate about mainstream education and whether it is detrimental to the self-perceptions of young people with intellectual disabilities, since it forces them to compare themselves with a more able reference group. Research evidence does appear to lend some support to this notion (Crabtree and Rutland, 2001; Kelly and Norwich, 2004). What also emerges is that stigmatised treatment is common in the wider community and so the type of school that the young person is attending may not be the only consideration (Cooney et al. 2006).

Kelly and Norwich (2004) found that age may be a factor in young people's self-perceptions of disability and their reactions to it. This was the only study to include different age groups as an independent variable. It is surprising that chronological age as an experiential factor has been given such little attention. This is because increasing age corresponds with increased opportunity to experience the self as different or experience stigmatised treatment.

Cunningham et al. (2000) and Cunningham and Glenn (2004) introduced a cognitive-developmental perspective to the area by measuring participants' verbal mental age. They reported that it was participants' developmental level (as indicated by verbal mental age) that was the key factor determining whether or not a young person had been told about and showed an understanding of Down syndrome. This research brings a new dimension to the area by highlighting the influence that cognitive-developmental factors may play in individuals' understanding of self as having a disability and a stigmatised identity. They concluded that a verbal mental age of around 5 years was the earliest stage a young person would show an awareness of Down syndrome. While this assertion generally fits with developmental models of children's understanding of other social categories, as was noted

earlier, this finding could simply reflect the fact that verbal ability was required to express an awareness using their measures.

Cunningham et al. and Cunningham and Glenn reported that few parents in their studies claimed to deliberately avoid the subject of Down syndrome with children who had significant verbal understanding to talk about the matter. This finding contrasts with Todd's (2000) view that significant others actively avoid talking about the subject of disability with their offspring for fear of causing hurt.

The papers in this review are varied but with the exception of Todd (2000), all the studies suggest that young people with intellectual disabilities are aware of their difficulties and limitations and have experienced stigmatised treatment from others. However, since all of the methods are based on verbal report, they may prevent those with more limited verbal ability from expressing their views. In addition, the views of younger children have been neglected altogether. Furthermore, issues regarding how children may develop self-perceptions relating to disability and stigma have been ignored. A developmental perspective was highlighted by Cunningham et al. (2000) and Cunningham and Glenn (2004). However, both of these studies took place at one time point and participants were aged 17 to 24. While verbal mental age was treated as an independent variable, the design of the study was not truly developmental, since change over time was not addressed. A way to take the previous research forward therefore would be to attempt to examine how an awareness of disability develops from a younger age.



## **Chapter 3: Development of Methods**

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### **3.1 Introduction**

The purpose of the following chapter is to describe in detail the process undertaken to develop a quantitative research method to explore the self-perceptions of children and young people with Down syndrome. The first step was to consider the cognitive needs and strengths of children with Down syndrome and how these could be used to inform such a method. The developmental literature on children's developing conceptions of social categories provided a rich research base from which a prototypical methodology could be taken. Individual tasks were chosen according to their suitability for the present research questions. The method chosen was primarily visual and required the development of photographs and the attainment of pictorial illustrations. The process whereby photographs were collected and pictorial representations procured will be described. Several pre-tests were undertaken to ensure the materials validity and suitability for the tasks, and this process of development will be detailed. Piloting of the tasks was carried out with a group of young people with Down syndrome. The outcomes of this piloting phase will be described, alongside the task refinements it led to.

### **3.2 Carrying out research with children with Down syndrome**

The first step in developing a method to investigate the views of children with Down syndrome was to consider the characteristics and needs of them as a participant group. Clearly, finding a way to elicit valid and reliable responses from children and young people with Down syndrome was essential. There were two strands of research pertinent to this concern. Firstly, research highlighting the challenges posed by child participants. Secondly, research on the particular cognitive strengths and weaknesses of young people with Down syndrome.

First and foremost, children with Down syndrome have limited linguistic competence. Therefore, techniques that rely too much on children's receptive or expressive verbal abilities are unlikely to collect valid or meaningful data (Davey, 1983). Researchers have also highlighted that children demonstrate a number of response tendencies. These include

children's tendency to agree with the researcher, give a series of 'don't know' answers, to be acquiescent, to respond in socially desirable ways, and to interpret questions in a literal manner. Such tendencies clearly impact upon the validity of children's responses (Lewis, 1992; Begley and Lewis, 1998). In addition, it must be borne in mind that children can be easily fatigued and distracted, which also endangers the validity their responses.

Developmental psychologists have produced guidelines to help others collect valid and reliable data from children. Their guidance includes the limited use of open questions, avoidance of questions inviting yes/no answers, being flexible in question wording and order, and the use of a range of response modes, pictorial multiple choice approaches being particularly suited to children (Lewis, 1995; Sigelman, Budd, Winer, Schoenrock and Martin, 1982; Lewis and Begley, 1998). Further, it is important to try to ensure that methods are inviting and engaging, as this will help to maintain children's attention and active participation (Davey, 1983).

All children with Down syndrome will have at least some degree of intellectual impairment (Wishart, 2005). Begley and Lewis (1998) suggest that choosing research tools suitable for younger typically developing children will help to ensure children with Down syndrome have the necessary capabilities to follow the tasks, and thus increase the likelihood of obtaining valid and reliable responses from them.

Researchers working from a behavioural phenotype standpoint further characterise the capabilities of children with Down syndrome by proposing that they demonstrate a particular set of behavioural strengths and difficulties (Fidler, Most and Philofsky, 2008). It has been reported that visuospatial processing tends to be strong (in that it has been observed to be comparable to that of typically developing children of the same mental age) relative to verbal processing (Jarrold and Baddely, 1997; Jarrold, Baddely and Hewes, 1999). In particular, visual memory and visual-motor integration appears to be strength of young people with Down syndrome (Fidler, 2005). Children with Down syndrome have been found to show difficulties with working memory and verbal short term memory (Byrne, Buckley, MacDonald and Bird, 1995). Language delays are characteristic of children with Down syndrome (Fidler et al., 2008). Young children with Down syndrome appear to show a relative strength in receptive compared with expressive language which becomes more pronounced as they approach middle childhood (Miller, 1999). Children with Down syndrome also show particular difficulties in sustaining attention (Landry and Chapieski, 1990).

It is increasingly recognised that the behavioural outcomes identified by this research are not merely the consequence of the genetic anomaly associated with Down syndrome alone. Instead, any behavioural outcome should be considered the result of the ongoing reciprocal influences of the cognitive capacities of the child and their social environment (Moore, Oates, Hobson and Goodwin, 2002). Further, such recognition also highlights that children and young people with Down syndrome are not the same, since such transactional processes will be subtly different across individuals. Hence, while care has to be taken when extrapolating from behavioural phenotype literature, it was believed that this research offered an important source of guidance. Consequently, the behavioural phenotype research helped inform the development of sensitive methods to tap into the perceptions of children with Down syndrome in the present study.

In sum, the preceding review suggested that the most suitable method for the present study would conform to the following specifications; firstly, the method should make minimal demands on participants' language skill and use visual stimuli. Further, making the stimuli interesting and meaningful should help to sustain young people's attention. By asking children to respond manually, the method will also be in keeping with their strengths (Begley, 1998; Rohr and Burr, 1978).

### **3.3 The search for a research method**

The psychological literature on children's developing conceptions of gender and racial categories was summarised in the introduction and help to provide a developmental indication of when an awareness of Down syndrome may be expected to begin. However, this body of research not only provided a rich source of developmental knowledge, but also methodological insights. The methods used in the vast majority of research looking at children's developing understanding of social categories and prejudice are rooted in the now classic studies by Horowitz (1936, 1939) and Clark and Clark (1939, 1947). Indeed, modern research owes much to the conceptualisations and techniques devised by these researchers. Therefore, their ideas will be briefly reviewed here.

Horowitz and Horowitz (1936) set out to investigate the development of prejudice in White children towards Black people. To do so, they needed a method they could use with participants who ranged in age from pre-school to their early teens. The researchers asked participants to choose between photographs of Black and White children according to

whom they would prefer to interact with in a variety of activities (sit next to in school, play with, sit next to at a show, come to your house for a long visit and take to town). Participants were also shown photographs of posed situations (such as, having dinner and playing marbles) in either segregated or mixed settings and asked which they would prefer to join. In a later study, Horowitz and Horowitz (1939) extended their technique to study the development of racial identity. They showed children portrait photographs of Black and White children and asked them to choose the ones they thought they most resembled. The Clarks (1939, 1947) adapted the Horowitz (1936, 1939) technique to investigate Black children's identity. Influenced by symbolic interactionist theory (Cooley, 1902; Mead, 1934), the Clarks were concerned that young Black people may develop a negative self-image as a result of their internalisation of society's negative view of them. The Clarks conceptualised racial identity as consisting of three elements: racial awareness, racial preference and self-identification. These elements were operationalised using three tasks. The Clarks used dolls instead of photographs. There were four dolls; two had brown skin and black hair and the remaining two had white skin and fair hair. Participants' preference was measured by asking them to attach value to the dolls by choosing which doll they 'liked the best' and which doll they thought was 'a nice colour', was 'nice' or was 'bad'. Participants' awareness was assessed by asking them to identify which doll was a 'Negro' (sic) and which was a 'White person'. Finally, participants were asked to choose which one 'looked like' him or herself (Clark and Clark, 1947). They found that participants were usually able to distinguish between races in the awareness section and the majority preferred the White doll. Moreover, a large proportion of children self-identified with the White doll.

The techniques that these researchers devised placed few demands on participants' linguistic comprehension or expression, as pictures were used to aid comprehension of the task and participants could point to indicate their response. The pictorial and doll stimuli also made the tasks interesting and the task was couched in the language of a game, thereby ensuring participants' motivation and engagement with the task. Furthermore, the technique provided a non-threatening method of communication with children on an extremely sensitive subject (Horowitz, 1939). In these studies it was clearly assumed that participants responded to the stimuli as if they were real. Children did appear to engage with the photographs as if they really were potential playmates and treated the imaginary activities as if they were really being offered. The pattern of children's responses also indicated they made meaningful choices. Furthermore, some participants were noted to

display extreme emotional reactions during the tasks, indicating they took them very seriously indeed. For example, when asked to identify which doll looked like them, children who had previously been cheerful became tearful (Clark and Clark, 1947). Variants of the techniques devised by the Horowitz' and Clarks' have been used successfully many times within the developmental literature. Today, the general trend has been to use photographs rather than dolls, since they are more lifelike (Wilson, 1987). The developmental literature was searched at length for potentially suitable tasks. The researchers assessed the usefulness of tasks through discussion. Finally, three tasks using pictorial stimuli were selected. The tasks were adapted in keeping with the needs and strengths of the participants and then piloted to check their efficacy.

### **3.4 Potential picture tasks for the study**

#### **3.4.1 Task 1: Self and Ideal-self Identification task**

This task was chosen to discover whether children with Down syndrome identify themselves as similar to others' with Down syndrome, and if such an identity corresponds with who they would like to be.

The task has been used in several previous studies investigating self and ideal-self identification, in relation to ethnicity and body size in children aged 3 to 10 years old (Wilson, 1987; Boulton and Smith, 1992; Cramer and Steinwart, 1998). In these studies, participants were shown photographs of same age and gender individuals who differed according to ethnicity or body size, and asked to choose between them in response to the question, "Who are you most like?" Then, to assess children's feeling toward their own identity, participants were then asked, "Who would you most like to be?"

#### **3.4.2 Task 2: Preference for Social Partners' task**

This task was chosen to assess participants feeling towards others with and without Down syndrome. In particular, it was hoped the task would tap into whether participants attached a value judgement to others with Down syndrome distinguishable from that attached to others who do not have Down syndrome.

Following Boulton and Smith (1992) participants were asked about their preferences for partners in various activities: play with in the playground, sit next to in class, have in your

team for a game, help you with school work and invite home to play. Similar tasks have also been used by previous researchers investigating children's preferences according to racial groups (Wilson, 1987; Davey, 1983). The ages of participants in these studies ranged from 7 to 11 years old.

The previous researchers presented stimulus photographs simultaneously for children's consideration and included photographs of both boys and girls. Thus, an array of photographs representing every possible combination of gender and ethnicity was presented to participants and they were simply asked to choose who they would prefer to engage in activities with. However, for the present investigation it was felt a diverse range of photographs may be overwhelming. Thus, to simplify the task, the photographs only depicted children with and without Down syndrome and same gender photographs were presented to participants, girls for girls and boys for boys.

In previous research, the same photographs were presented for each activity. However, having simplified the task substantially, it was thought that using the same photograph pair for every activity carried the risk that children would base their decision on some variable other than Down's syndrome, unbeknown to the researcher. Thus, to strengthen the validity of the task six different photograph pairs (a child with Down syndrome and a child with no disability) were required (one pair for each activity).

In previous studies a verbal description of the activities was given to participants. However, given the verbal difficulties of children with Down syndrome, this verbal component of the task was not deemed suitable. Thus, in order to aid comprehension of the task and to make it more interesting, it was decided that the activities in the present study be represented by coloured illustrations.

It was also decided that an active response mode would be most engaging and in keeping with the children's strengths. Thus, following Davey (1983), a posting box format was chosen for the task.

### **3.4.3 Task 3: Adjective Attribution task**

This task was chosen to examine whether children hold distinct ideas about others with Down syndrome that correspond to popular stereotypes and ideas about what it means to

have a disability. It has been used by previous researchers to investigate the awareness and endorsement of ethnic stereotypes (Davey, 1983; Boulton and Smith, 1992) and stigma related to body size (Cramer and Steinwert, 1998). The participants in these studies ranged in age from 3 years to 11 years old.

Using a post-box game format, Boulton and Smith (1992) presented participants with three posting boxes identified with photographs depicting children of three different ethnicities. Participants were then handed 14 cards, one at a time, on which an adjective was written. The adjectives reflected the common stereotypes of ethnic minorities, such as 'lazy' and 'dirty'. Participants were asked to post each of the 'messages' to the photographed people they thought each one applied to best. If participants thought the 'message' applied to more than one person, they were asked to hand it to the researcher. A box identified as 'nobody' was also included to give participants that option if they wished. In practice however, the researchers reported that the latter two options were seldom used.

The descriptors for the present study were identified in the first instance during a brain storming session with a colleague and Developmental Psychologist. The descriptors chosen either reflected the popular stereotype of people with Down syndrome, were misconceptions about children with an intellectual disability that may arise in a classroom or referred to observable potential experiences of people with Down syndrome and/or intellectual disability. The polar opposite of each of the descriptor was also identified. For example, 'happy' and 'friendly' both feature in the popular stereotype of people with Down syndrome (Wishart and Johnston, 1990). 'Naughty' may be how, in some instances, the behaviour of a child with an intellectual disability in a classroom may be perceived and also corresponds to the popular stereotype that people with Down syndrome are 'mischievous' (Wishart and Johnston, 1990). The descriptors 'needs help' and 'gets called names' relate to what having a disability might mean for some children. The adjectives and their polar opposites may be found in table 13.

**Table 13: Polar opposite adjectives for the Adjective Attribution task**

Down syndrome adjectives	Polar opposite adjectives
Different from everyone else	Same as everyone else
Feels happy most of the time	Feels sad most of the time
Is naughty	Is good
Needs help to do things	Can do lots of things alone
Is stupid	Is clever
Lonely	Has lots of friends
Friendly	Unfriendly
Gets called names	Doesn't get called names

Previous research represented the adjectives using simple text, however, given many young people with Down syndrome have difficulties with reading this was deemed inappropriate. Thus, the present study represented the adjectives using colour illustrations. The use of pictorial stimuli is in keeping with the strengths of children and young people with Down syndrome.

Another question was how participants viewed themselves in relation to others with Down syndrome. Therefore, in addition to photographs of children with and without Down syndrome, a self-portrait photograph was included in the task. Following Boulton and Smith (1992), a posting box format was also used in this task. Thus, there were three posting boxes with different photographs attached, one with a photograph of a child with Down syndrome, one with a child with no disability and one with the participant's self-portrait. The children depicted in the photographs were the same gender as the child participant.

The quality of the materials for these tasks was crucial. This chapter will now turn to describe what details were considered in developing the task materials.

## **3.5 Collection and development of materials**

### **3.5.1 Photographs**

The quality of the photographs was fundamental to the effectiveness of the above tasks. Consequently, a great deal of thought was given as to what specifications they should meet. The basic requirements of the tasks dictated that the photographs should depict the heads-and-shoulders of individuals with and without Down syndrome looking directly at the camera and not wearing spectacles or any item of clothing or hairstyle that obscured their



face. The photographs should also have a uniform background of a neutral colour, to ensure participants' attention was drawn firmly to the photographed persons.

Consideration was also given to other features of the photographed children, such as their clothing and hairstyle. There were arguments for and against keeping these features constant. For example, while such features may comprise a distraction from the variable of interest, it was also recognised that a set of photographs differing solely on one dimension would lack the variety encountered in everyday life. In the end, two factors dictated the conclusion reached. Firstly, it was reasoned that these features would vary to such a degree across all of the photographs that any potential confounding effect relating to a particular look would be washed out. Secondly, it would be a considerable logistic challenge to obtain a set of photographs of young people wearing similar clothing.

Several avenues were explored to obtain photographs for the tasks, with varying degrees of success. The first port of call was the charitable organisation Down's Syndrome Scotland. The organisation was asked if they owned any photographs that may be used. However, despite their best efforts, this strategy was largely fruitless. The main problem was that the photographs Down's Syndrome Scotland had did not meet the basic specifications identified, as they tended to show children engaged in activity and wearing their spectacles. The organisation also assisted by posting a call on their website for parents to email photographs to the researcher. However, there was a very low response rate to this request. The final photographs came from three sources. One was a local amateur dramatics/theatre group that catered for children and young people with Down syndrome and their siblings, who kindly allowed the researcher to visit and take photographs of their members. Another source was an internet photograph site named Flickr.com. This was searched at length for suitable photographs. The relevant photographers were then contacted via the site for consent and asking for a copy of the original picture file, to ensure high standard of print quality. Finally, colleagues were approached and asked for photographs of their children.

A critical characteristic of the photographs was that they should depict individuals of a similar age to the participants. The age of the photographed children was considered important because for participants to engage in the task properly they should be able to relate to the individuals in the photographs. This was particularly important for the preference task, since the idea behind the task was that participants should view the individuals in photographs as potential playmates. Thus, to ensure the relevance of the task and validity of participants' responses, photographs of similar aged young people were

crucial. When it was first considered how similarly aged photographs of young people could be obtained this proved challenging because of the wide age range of participants involved. However, research carried out in the 1960s and 1970s about children's ability to estimate other young people's ages suggested that, while there is a progressive improvement as they grow older, children's ability to judge others' age does not appear to be finely tuned. Kratochwill and Goldman (1973) presented children with pairs of photographs depicting individuals that represented four levels of the life span: infancy, childhood, adolescence and adulthood. Children aged 3 to 9 years old were shown every possible combination photographs and asked to judge if they were the same size or which was older. The children's accuracy improved from 47% at age three to 59% at age six and 100% at age nine. For the present investigation it was reasoned that, so long as the apparent age of those depicted in the photographs did not appear to be below 10 years of age or over 16 years of age, then the photographs would be relevant for participants.

To help ensure that the photographs were of children of the correct age group, the photographs that were obtained underwent a pre-test. Ideally, this would have been carried out with a group of children of similar ages to the intended participants. However, the researcher was conscious that the participant pool was small and was wary of employing potential participants for pre-test purposes. Thus, an opportunistic sample of adults was asked to complete the pre-tests. A group of adults ( $n= 15$ ) provided judgments of the photographed individual's age, by free response. Photographs that were frequently thought to be aged under 10 or over 16 years of age were dropped from the task materials. The attractiveness of the photographed individuals was also identified as potentially confounding the variable of interest. The 'beauty-is- good' stereotype has received much support since its original conception in the seminal study by Dion, Berscheid and Walster in 1972 (see Langlois et al., 2000 for a review). This work contested that, adults, young children and infants prefer attractive to unattractive individuals. Therefore, it was necessary to pair the photographed children with and without Down syndrome according to attractiveness, to ensure participants made the desired comparisons.

Previous research has found that children and infants agree with adults about who is and who is not attractive (Dion, 1973; Langlois, Ritter, Roggman and Vaughn, 1991; Langlois, Roggman, Casey and Ritter, 1987). Thus, in order to control for the attractiveness of the photographed young people, the same group of adults asked to judge the age of the

photographed individuals (n=15), were also asked to provide attractiveness ratings for the photographs on a 5-point Likert scale.

The aim was to match each photographed child with Down syndrome to one without Down syndrome according to attractiveness, so that each pair of photographs was of equivalent attractiveness. Unfortunately, attractiveness proved to be particularly difficult to control for due to a combination of two factors. Firstly, the pictures of young people with Down syndrome tended to be judged at the lower end of the scale. Alone this factor would not have posed a problem, as they would simply be matched with those without Down syndrome of an equivalent low level of perceived attractiveness. However, a large proportion of photographs of the non-disabled young people came from an internet site where professional and budding photographers showcase their work. Consequently, many of the non-disabled young people photographed were at the high end of an attractiveness scale. Thus, taken together, these factors meant that it was difficult to match the individuals' photographs according to their absolute attractiveness. The limited availability of photographs in the first place meant that finding suitable replacements was virtually impossible in a reasonable time-scale. The solution was to use the median attractiveness scores to match the photographs of children with and without Down syndrome according to their rank order of attractiveness.

It was also important that the emotion expressed by the children in the photographs should be uniform. The aim was to obtain photographs of children showing either neutral or positive affect. In practice, it was much easier to obtain photographs of children and young people expressing positive affect. Therefore, this became the criterion expression. In order to control for the emotionality of photographed individuals, the group of adults (n=15) were also asked to provide a free response describing the expressed emotion of each photograph. Photographs that received a response of anything other than positive emotionality were dropped. For example, some of those excluded from the set of materials were judged as looking 'angry' or 'sad'.

The adults (n=15) asked to offer initial judgments about the photographs were finally asked to indicate whether they thought each photograph depicted a male or female, and whether they thought each photograph depicted an individual with or without Down syndrome. Those that were not reliably judged correctly according to gender and as having Down syndrome were excluded.

The resulting set of photographs was further developed using Photoshop. The backgrounds of the photographs were deleted and replaced by a uniform neutral beige colour. The photographs were cropped so that only the heads and shoulders of the children in the photographs were visible. Further, all the photographs were sized to ensure the heads of all the children in the photographs were roughly the same.

The collection and development of the photographs required for the tasks constituted a much greater challenge than was anticipated. It took seven months to track down suitable photographs that were of a reasonable quality and that also met the specifications of expressed emotion, age group and clear view of the face of the child. Then a further three months was required to develop them for use.

### **3.5.2 Developing the pictorial illustrations**

The Preference for Partners and Adjective tasks both required the development of colour pictures to illustrate the target activities and adjectives. These illustrations were developed in collaboration with a graphic designer.

The first step was to formulate a brief for the graphic designer and this was achieved through discussion among the research team and by holding a focus group with young people. Initial thoughts regarding the illustrations were that, in contrast to previous research, there should be no text accompanying the illustrations and they should have enough explanatory power on their own. This was to ensure that participants who may have difficulty with reading were not alienated. It was also important that the illustrations be as true to life as possible in their representation of people, as this would help participants identify with the pictures and prevent the illustrations from looking too childish (as is the danger of more cartoon-like representations). The activities also had to be represented in such a way as to appeal to and be relevant to children across the age range of participants involved. For instance, 'play with in the playground' could easily be depicted in very different ways for an 11 and a 16 year old. However, there are also activities that both an 11 and 16 year old might engage in whilst in the playground, such as chatting with friends and throwing a ball around.

A key stage in developing a brief for the adjectives task was to find out how children conceptualise the words and phrases selected for the task. This was achieved by holding an

informal focus group with six children whose age ranged from 5 to 12 years old. The children were asked what they thought the adjectives meant, if they could think of an example of each one and how they would draw it. The responses the children had provided during the focus group were an invaluable source of inspiration, and enabled the researcher to provide the graphic designer with ideas that would help ensure the resulting pictures were easily understood by young participants.

The resulting brief was then given to the graphic designer, who made first drafts of all the illustrations. The illustrations subsequently went through several stages of development, with further changes made in collaboration with the graphic designer. There were two aspects of the images that required several modifications; stylistic features and conceptual features. Stylistic features included making the point of view as realistic as possible and having background features that helped give the images context. Conceptual changes that were made involved the finer details of how the descriptors were represented. For example, the 'needs help to do things' picture initially showed an adult sitting next to a child pointing at a school book, while the second picture showed an adult selecting a book from a bookshelf as the child stood next to her. This image was tweaked by asking for the teacher in the first image to be looking at the child and leaning in sympathetically and in the second picture having the teacher with one hand on the child's shoulder and the other one the bookshelf. The key changes made to illustrations may be seen in figures 2 and 3 below.



**Figure 2: First version of 'sit next to at lunch', point of view amended**



**Figure 3: First and second versions of 'needs help'. The illustration on the right was improved by adding background features and having assistant lean towards child**

To ensure that the activities and descriptors depicted in the illustrations were readily and accurately identifiable, the illustrations were piloted with a group of four children with Down syndrome aged 14 years old.

### **3.6 Piloting the illustrations**

#### **3.6.1 Preference for Social Partners' task**

Each child was asked "What do you think this picture shows?" for each of the six illustrated activities. Table 14 below details their responses.

**Table 14: Children's comments during piloting of the Preference for Social Partners' task**

Activity	Quotes from children
Play with in playground	Playtime (girl aged 14) Chatting and football (boy aged 14)
Sit next to in class	Sitting in class (girl aged 14) Class (boy aged 14)
Sit next to at lunch time	Lunch time (girl aged 14) Eating lunch (boy aged 14)
Have in your team for a game	Running and picking teams (girl aged 14) Football (boy aged 14)
Help you with school work	Writing and helping (girl aged 14) Working (boy aged 14)
Invite home to play	Friends listening to music (girl aged 14) Singing (boy aged 14)

Children responded well to these illustrations and their comments were generally in the right domain. The researcher was then able to provide guidance as to the specific nature of the activity being represented. For instance, for the invite home to play illustration, if the child said the picture showed friends listening to music, the researcher added to this by saying, "Yes they are and do you think that the girl has asked her friend to her house to listen to music?" The researcher's input was met with agreement and little scaffolding was required to help participants understand the precise nature of the pictures. Thus, participants responded well to the illustrations for the preference task.

### 3.6.2 Adjective Attribution task

The illustrations for the Adjectives task also underwent piloting to ensure they were easily comprehensible. The same group of four children were asked to tell the researcher what they thought about each picture. The children tended to be very literal in their interpretations. The abstract nature of the descriptor 'different from everyone else' proved to be difficult to represent and the resulting illustration was not readily grasped by participants. Therefore, this descriptor pair was dropped from the task.

The final descriptors and representative quotes from the young people who helped to pilot them are found in table 15.

**Table 15: Final descriptors for Adjective Attribution task and quotes from young people**

Adjective Illustration	Typical quotes from children
Sad	Sad (girl aged 14)
	Feels sad (boy aged 14)
Happy	Happy (girl aged 14)
	Happy (boy aged 14)
Good	Working (girl aged 14)
	Working on own (boy aged 14)
Naughty	Bad to friend (girl aged 14)
	Pulls hair (boy aged 14)
Needs help	Helpers (girl aged 14)
	Teacher (boy aged 14)
Can do things	Looking at books, reading (girl aged 14)
	Reading (boy aged 14)
Clever	Everything right, work's good (girl aged 14)
	First place (boy aged 14)
Lots of friends	Friends (girl aged 14)
Not many friends/ lonely	Sad, no pals (girl aged 14)
	Sad, bullies, no friends (boy aged 14)
Stupid	All wrong, sad (girl aged 14)
	Wrong answer, sad (boy aged 14)
Friendly	Waving to a boy in town (girl aged 14)
	Saying hi (boy aged 14)
Not friendly	Angry (girl aged 14)
	Cross (boy aged 14)
Gets teased	Horrible to him (girl aged 15)
	Shouting (boy aged 14)
Doesn't get teased	Friends (boy aged 14)



Again, some guidance as to the precise meaning of the illustrations was required. For example, if the child said, "she's working hard", the experimenter added, "yeah, and that's being good, isn't it?" This type of guidance was met with agreement from the participants. During the piloting of the illustrations it was noted that their meanings were more transparent and easily understood by participants if they were presented in pairs, alongside their polar opposite. For example, the character in the 'not friendly' image was often thought to be angry; however, when paired with its polar opposite 'friendly', its meaning was immediately apparent. This was noted for further development of the task procedure. This presentation style is also similar to that proposed by the Harter and Pike (1985) Self-perception scale.

### **3.7 Piloting the tasks**

#### ***Participant group***

Eleven young people aged 14 to 16 years old (4 girls and 7 boys) who attended two Moderate Learning Needs schools in Glasgow helped to pilot the measures. However, not all of these participants were used to pilot all tasks, as the tasks were refined gradually and piloting was staggered across participants. It was recognised that it would have been better to pilot the task with a larger group of participants. Table 16 shows what tasks each participant helped to pilot.

**Table 16: Details of participants who helped to pilot tasks**

P	Gender	Age	Self-Ideal self age	Self- Ideal self gender	Self - Ideal self disability	Sorting/ Self-identification	Preference task	Adjective task
1	M	14	.	.	*	.	*	*
2	M	16	*	.	*	.	*	.
3	F	17	*	.	*	.	*	.
4	F	14	.	*	*	.	*	.
5	F	14	.	*	*	.	*	.
6	F	14	.	*	*	.	*	.
7	M	14	.	*	*	.	*	.
8	F	15	.	.	.	**	**	**
9	F	15	.	.	.	**	**	**
10	M	14	.	.	.	**	**	**
11	F	15	.	.	.	**	**	**

\*\* Data used in final analysis

### 3.7.1 Task 1: Self and Ideal-self Identification task

#### 3.7.1.1 Participants

The measure was piloted with seven young people with Down syndrome aged 14 to 16 years old (4 girls and 7 boys), who attended two Moderate Learning Needs school in Glasgow.

#### 3.7.1.2 Research questions task was intended to answer

1. Do participants with Down syndrome identify themselves as similar to others who have Down syndrome?
2. Does the participant's identity correspond to their desired identity?

### **3.7.1.3 Procedure**

Participants were presented with two photographs, each depicting a child the same gender as themselves. The photographs differed, in that one depicted a child with Down syndrome and the other a child with no disability. Participants were asked to point to the photographed child that they "were most like". A different photograph pair was then presented and participants were asked to point to the photographed child they would "most like to be". Participants were also asked to explain their choices in order to assess comprehension of the task instructions.

### **3.7.1.4 Findings**

During the piloting phase, the usefulness of the self and ideal self identification task became increasingly questionable. The first participant to pilot the task chose the typically developing photographed child in response to both the 'self' and 'ideal-self' questions. However, the researcher felt that the participant was uncertain of what he was being asked to do. It was therefore considered that a trial task may aid participants' comprehension of the task. Edwards and Lewis (1979) reported that children aged 3 to 5 years old could sort and classify photographs of persons aged 1 to 70 years old into 'children' and 'adults', and correctly identify themselves according to these categories. Therefore, it was reasoned that age categorisation may comprise a useful practice trial in the task. Participants were asked to choose from a photograph of an adult and a photograph of a young child in response to the same two questions. Unfortunately, the inclusion of this trial did not increase confidence in the task. Two participants (one girl and one boy) did not correctly identify themselves according to age. The reasons participants gave for their responses centred on features such as hairstyle or other idiosyncratic inferences (e.g. they're cool). It was possible that age may have been too subtle a categorisation for the young people to make. Moreover, it may also have been the case that the young people considered other features in the photographs to be more salient than age. Therefore, age was replaced with gender, as it was thought that it would constitute a much starker contrast. For the remaining four participants the practice stage of the task used gender as the discriminating factor. It was found that participants did not respond consistently according to gender categories either and their comments suggested that they continued to respond based on other details of the photographs.

While the participants' responses may have reflected something about the meaning of age and gender to the participants, it was more likely that the children just had a poor understanding of the task. There was no way of telling if the task was meaningful and relying on a single response by participants made the validity difficult to gauge. Consequently, this task was abandoned and the utility of another approach was explored. Table 17 shows the data from the piloting of the self and ideal-self identification task. The first four columns show responses for the two sets of practice questions. The first set of practice trials involved age (young child vs. adult) comparison and the second set used a gender comparison. The last two columns are the task trials proper and show participants' responses and comments they made when asked to explain their choices.

**Table 17: Participant responses and comments during piloting of Self and Ideal-self Identification task**

**NB. Non-disabled photograph selected (ND); Down syndrome photograph selected (DS)**

p	Gender	Age	Self (age)	Ideal-self (age)	Self (gender)	Ideal-self (gender)	Self (disability)	Ideal-self (disability)
1	M	14	.	.	.	.	ND	ND
2	M	16	Adult "perfect"	Same age "cool one"	.	.	DS	DS and ND
3	F	17	Adult "long hair"	Adult	.	.	ND	ND "pony tail"
4	F	14	.	.	Male "brown hair"	Female	DS "beautiful"	ND
5	F	14	.	.	Female "smiling"	female	ND	DS
6	F	14	.	.	Female "cool"	Female	ND "beautiful"	DS
7	M	14	.	.	Male	Female	ND	ND

### 3.7.2 New task 1: Person Sorting and Self-identification task

To replace the Self and Ideal-self identification task, a sorting task previously used by Weinraub, Clemens, Sockloff, Ethridge, Gracely and Myres (1984) to investigate gender awareness in children aged three years old was chosen. In the present study, this task was used to discover if children were mindful of Down syndrome as a social category when viewing others and whether or not they identified themselves as similar to others with Down syndrome. This task was thought to have two main advantages over the self and ideal self identification task. Firstly, it was reasoned that it may be a more sensitive test of

participants' awareness of the facial features associated with Down syndrome, since it involved more than one pair of photographs. Secondly, it was thought that the act of sorting through pictures of other young people with and without Down syndrome may act as a primer for then thinking about themselves in terms of Down syndrome, if indeed they used Down syndrome as a sorting criterion.

### **3.7.2.1 Participants**

Four of the participants who took part in the piloting of the Self and Ideal-self identification task helped to pilot the new task. They were aged 14 to 15 years old and three were girls and one was a boy.

### **3.7.2.2 Research questions the task was intended to answer**

1. Do participants choose to sort photographs of people the same age and gender as themselves according to the social category Down syndrome?
2. Do participants identify themselves as similar to others with Down syndrome?

### **3.7.2.3 Procedure**

In following Weinraub et al. (1984), participants first completed a trial task to ensure that they understood the sorting principle and were able to sort according to basic categories. To increase participant involvement with the task and in keeping with children's preferences for manual response options, a post-box game format was again chosen for this task. Two posting boxes were presented on a table in front of the child. On one box a picture of a blue everyday object was placed, while on the other a red coloured object was placed. One at a time, and in a random order, eight picture cards were placed in front of the two boxes (four of these depicted red objects and four depicted blue ones). After the participant had looked at each picture card, they were asked to put it into one or other box according to the picture it was the "same as".

Having successfully sorted according to colour, the child was invited to engage in a similar activity, this time involving photographs of children with and without Down syndrome. Eight stimulus photographs depicted four children with Down syndrome and four with no

disability. Participants were handed each of the stimulus photographs one at a time as asked to put each one in the box along with the photograph it was most like.

The child was then shown a self-portrait photograph and, after self-recognition was checked, asked to put it into one of the two boxes according to which they thought their self-portrait was most like.

### **3.7.2.4 Findings**

Three of the participants immediately understood the practice colour sorting task. The remaining individual required some initial guidance from the researcher, but thereafter successfully completed the practice sorting task. Having placed the first picture in the incorrect box, the researcher provided guidance by saying, “that’s a good try, but I think this picture goes here. Let’s try another one”. This prompt appeared to be sufficient and so was used with other participants for whom the task was not immediately clear.

During the task proper, participants were found to engage well with the task. This was evidenced by their attention to the photographs and thoughtfulness when placing each one in their chosen box. The data from the piloting of this task is shown in table 18.

Participants’ responses were not always ‘correct’, however, the main concern when piloting the task was comprehension and engagement.

The participants also performed well on the self-identification part of the task when it was piloted. All children immediately identified the photograph of themselves. However, none of the children identified with the child with Down syndrome.

**Table 18: Participant responses during piloting of Sorting and Self-Identification task**

P	Gender	Age	Sorting DS Score	Self-identification
8	F	15	7	ND
9	F	15	5	ND
10	M	14	4	ND
11	F	15	4	ND

### **3.7.3 Task 2: Preference for Social Partners' task**

#### **3.7.3.1 Participants**

The same group of four participants as above helped to pilot the Preference for Partners' task.

#### **3.7.3.2 Research question task was intended to answer**

1. Do participants show a preference to engage in pictured activities with a child with or without Down syndrome?

#### **3.7.3.3 Procedural issues**

For the Preference for Partners' task, it was necessary to experiment with the different ways the task could be presented to participants, in order to choose that which was most easily comprehended, valid and pragmatic to deliver.

The main options considered were whether to present the photographs or illustrations on the boxes. Initially, the plan was to present the two photographs (one depicting a child with Down syndrome and the other a child with no disability) on two boxes for paired comparison and ask the child to post each activity picture one at a time into one of the boxes according to which person they preferred to engage in activities with. While this seemed to be a straightforward approach and easy for the participants to grasp, using the same pair of target photographs for every activity meant that this method lacked strength as a valid measure. This was because although the photographs had undergone several pre-tests to control for age, attractiveness, gender and disability status, even assuming these were completely successful, it was not possible to control for other features of the children in the photographs, such as, hairstyle or clothing. Therefore, despite best efforts at control, the possibility would remain that children merely prefer one photograph over the other for some reason other than the fact that the child in the photograph had Down syndrome or not.

One way to increase the task's strength was to use a different pair of photographs for each activity. However, since this meant changing the photographs on the boxes for each activity picture, it was not the most pragmatic method of presentation to deliver. As a result, this method was used during the piloting phase for the first participant only.

Maintaining the interest and engagement of the participant was of prime importance, thus the task presentation was a crucial consideration. In an effort to improve this aspect of the task, in subsequent piloting the activity pictures were placed one at a time, on a single box. For each activity two photographs were placed in front of the box for comparison (one depicting a child with Down syndrome and the other a child with no disability) and the child asked to choose which of the photographed children they would prefer to engage in the activity with and post it into the box.

### **3.7.3.4 Findings**

This task made sense to the children immediately. Their engagement with the task and enjoyment of it was clear from the outset. Table 19 shows the preference shown by participants for the photographed child with Down syndrome.

**Table 19: Participant responses during piloting of Preference for Social Partners' task**

P	Gender	Age	Preference shown for DS photo
1	M	14	2
2	M	16	0
3	F	17	3
4	F	14	1
5	F	14	1
6	F	14	2
7	M	14	0
8	F	15	2
9	F	15	3
10	M	14	3
11	F	15	3

## **3.7.4 Task 3: Adjective Attribution task**

### **3.7.4.1 Participants**

The same four participants above helped to pilot the adjective task.



### **3.7.4.2 Research question task was intended to answer**

Do children hold ideas about others with Down syndrome in line with social stereotypes of Down syndrome?

How do children view themselves in relation to these ideas?

### **3.7.4.3 Procedural issues**

Previous investigators who used this task (Boulton and Smith, 1992) presented participants with post boxes identified by photographs of people of different ethnic groups. They then showed participants 7 positive and 7 negative adjective cards and asked them to attribute each one independently to the photographed individuals by posting the cards into the appropriate box. Four posting boxes were presented to participants simultaneously. Three boxes were identified by photographs of a boy and girl from each of three ethnic groups and the fourth labelled 'nobody'. If participants thought the adjective fitted more than one person, they were instructed to pass it to the experimenter. However, the authors report that this last option was seldom used. If children thought it fitted no one, they were instructed to post it in the 'nobody' box.

The notion of a 'nobody' box was considered to be rather abstract and ill suited to children's intellectual disabilities. Thus, participants were in effect being asked to make a forced choice between the photographs when attributing the adjectives. With these considerations in mind, this task was presented in a different manner in the present study.

Three boxes were used, one identified by a photograph of a child with Down syndrome, the other a photograph of a child with no disability (both the same gender as the participant) and finally the child's self-portrait photograph. These were presented one at a time. During the piloting of the descriptors for this task, it was noted that the illustrations were more readily interpreted when presented in pairs, that is each descriptor and its polar opposite. In order to incorporate this into the task design, the descriptors were presented one pair at a time, and participants were asked to choose which descriptor (for example, 'good' or 'naughty') applied to the photograph on the box. Participants were instructed to post the chosen descriptor into the box and leave the other on the table. This comparison process was repeated for each of the seven descriptor pairs and each photograph.

While this task worked well, it became apparent immediately that it was laborious to deliver. As a result, this procedure was only used with the first pilot participant. The

presentation format of the task was then switched so that the descriptors were presented on two boxes. The participants were then handed the three photographs, one at a time, and asked to post the photographs into the boxes according which descriptor described the child best. This mode of presentation required a larger number of photographs (28 photographs of boys and girls with and without Down syndrome). However, this method of presentation improved the task. Not only was this approach easier to deliver and was engaging for the participants, but using a different photograph pair for each descriptor pair gave more confidence that participants were making choices based on the features of Down syndrome. The task was piloted using this method of presentation with four participants (data presented in table 20).

#### 3.7.4.4 Findings

Participants enjoyed and engaged well with the pictures and photographs. There were no issues with perseveration and participants' appeared to be making distinct and meaningful choices for the different photographs, often taking time to consider their responses.

**Table 20: Attributions made to three photographs during piloting of Adjective task**

P	Gender	Age	Adjectives attributed to DS photograph	Adjectives attributed to ND photograph	Adjectives attributed to self photograph
8	F	15	Not friendly, naughty, lonely, happy, clever, needs help, called names	friendly, good, has friends, happy, clever, can do things, called names	friendly, good, has friends happy, clever, can do things, doesn't get called names
9	F	15	friendly, naughty, has friends, happy, clever, needs help, called names	not friendly, good, lonely, happy, stupid, can do things, called names	friendly, good, lonely, sad, clever, needs help, doesn't get called names
10	M	14	friendly, good, lonely, happy, clever, needs help, called names	friendly, good, has friends, sad, stupid, needs help, called names	friendly, good, has friends, happy, clever, can do things, doesn't get called names
11	F	15	friendly, good, has friends, sad, stupid, needs help, called names	not friendly, good, lonely, happy, clever, can do things, doesn't get called names	friendly, good, has friends, sad, clever, can do things, doesn't get called names

#### 3.7.5 Summary

At the end of the piloting phase, the following three tasks were selected for the experimental component of the present study: i) The Person Sorting task, which was intended to measure awareness of Down syndrome and self-identification with Down syndrome; ii) The Preference for Social Partners' task, intended to measure participants' attitude towards sharing activities with others with Down syndrome; and finally, iii) The

Adjective Attribution task, which was intended to discover if participants held particular views about others with Down syndrome compared to non-disabled peers and how they saw themselves.

The following chapter will describe the design and general method for the experimental part of the study, before going on to detail the methods and results for each task in turn.

## **Chapter 4: Method of Experimental Studies**

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### **4.1 Experimental design**

The study employed a 2 (age group: younger and older) x 2 (disability: Down syndrome and no disability) between subjects factorial design. A comparison group of children with no disability was sought because it allowed the researcher to discover if having Down syndrome led to differences in task performance. However, because children with Down syndrome have at least some degree of intellectual impairment, it was necessary to control for cognitive ability as well as age, using two groups of non-disabled participants. The cognitive ability control group enabled the researcher to ensure, as far as possible, that any differences in task performance that occurred could not be attributed to differences in participants' cognitive ability. The British Picture Vocabulary Scale (BPVS-II; Dunn et al., 1997) was selected to match a group of non-disabled participants to those with Down syndrome according to cognitive development. The BPVS-II assesses verbal comprehension and provides a score that may be converted into an approximate verbal mental age (VMA). The BPVS-II is commonly used to provide a brief measure of cognitive development, because it is argued that vocabulary subtests in comprehensive tests of intelligence are highly correlated with overall mental age and IQ (BPVS-II manual, p. 35-36, Dunn et al., 1997). Verbal comprehension was also considered to be a critical factor in terms of the participants' ability to understand instructions and thus participate meaningfully in the tasks. Whilst it would have been advantageous to have carried out a fuller assessment of cognitive abilities for the purpose of group matching, it would have placed a considerable burden on the participants. The BPVS-II has the additional advantage of being accessible and enjoyable for young people (Glenn and Cunningham, 2005). A second group of non-disabled participants were matched to those with Down syndrome on chronological age (CA). This helped to ensure that any differences in task performance between these groups could not be due to social experience and learning acquired with age.

### **4.2 Power calculation**

There were no data from previous research studies that could be utilised to calculate an expected effect size for any of the tasks in the present study. Nor could an estimation of the expected effect size be made using pilot data, since the group of participants used to pilot

the tasks was small. Consequently, the conventions proposed by Cohen (1988) were used to inform such a calculation. Therefore, Cohen's conventions provided the best guide available under the circumstances (Howell, 2007). A medium effect size is generally regarded a reasonable assumption in social psychological research (Cooper and Findley, 1982; Cohen, 1992). The values provided by Cohen (1988) for a One-way ANOVA were utilised because this study involved examining differences in scores between three groups of participants (participants with Down syndrome and two groups of participants without Down syndrome). To have an 80% chance of detecting a medium effect size ( $f = .25$ ) at the alpha level .05 (two-tailed), the necessary sample size per group is 52 for a three group experiment (Cohen, 1992). However, it was anticipated that the recruitment of children with Down syndrome would pose a significant challenge. Consequently, at this exploratory stage, a compromise was sought. According to Cohen's (1992) tables, 30 participants in each group would give .80 power to detect a large effect ( $f = .40$ ) at the alpha level .01. Therefore, the researcher aimed to recruit 30 children with Down syndrome and 60 typically developing children, 30 matched on chronological age and 30 matched on VMA.

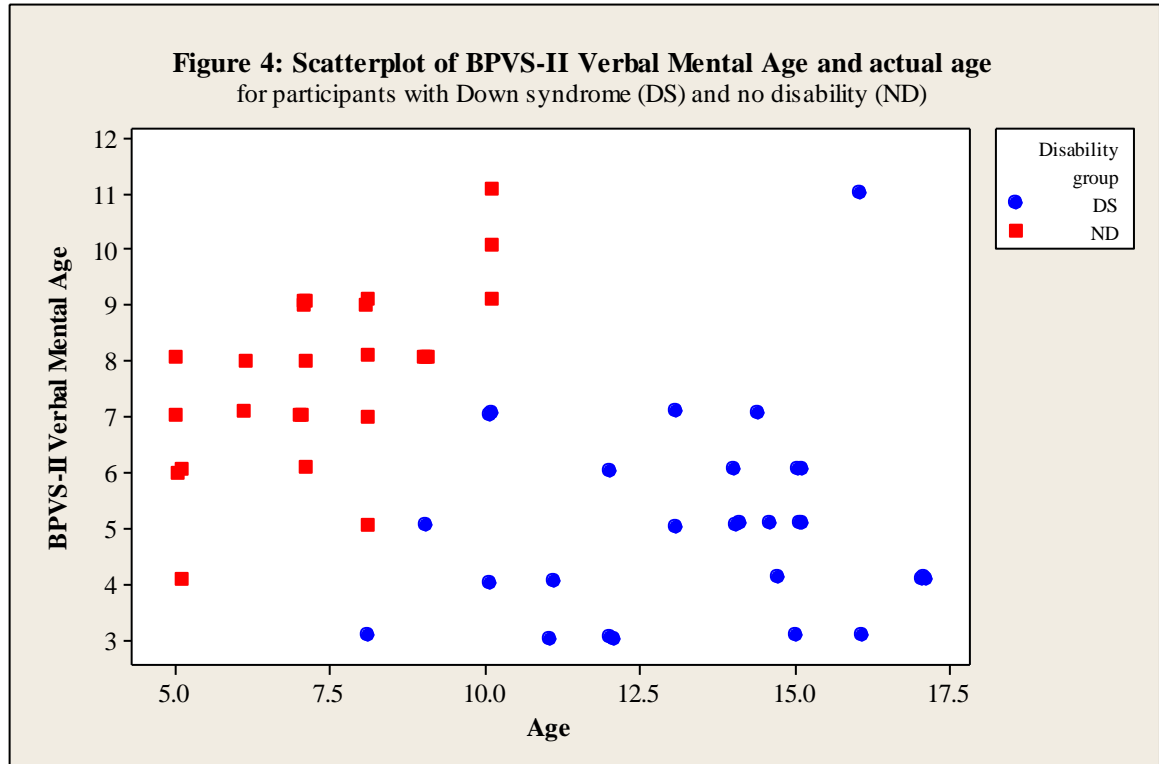
### 4.3 Participants

The sample of children with Down syndrome comprised 18 girls and 10 boys. The ages of participants in the Down syndrome group ranged from 8 years and 8 months to 17 years and 9 months old, and their mean verbal mental age, generated by their score on the BPVS-II, was 5.05 (SD= 1.77).

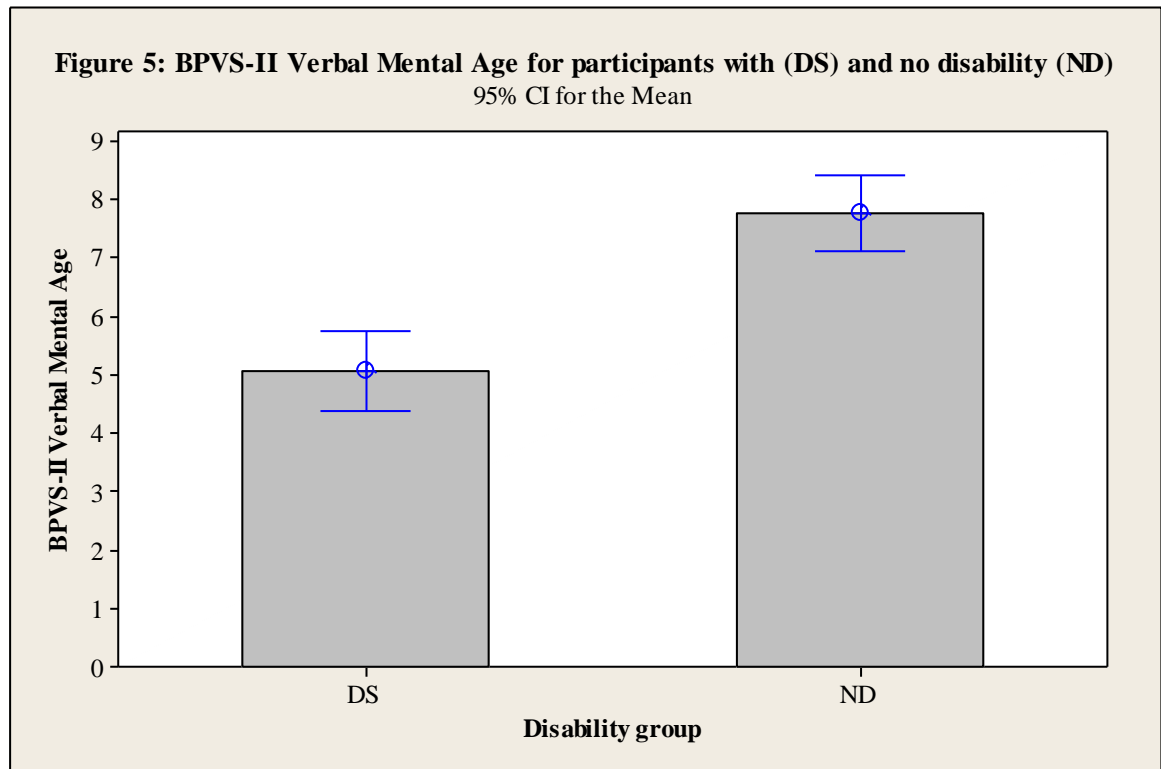
The study was designed to incorporate two control groups of participants with no disability; one matched according to chronological age and the other according to verbal mental age (as indicated by scores on the BPVS-II). Unfortunately a verbal mental age matched group was not obtained. This was because the sample of participants ( $n=25$ ) recruited to be the verbal mental age control group, actually scored consistently higher on the BPVS-II than participants with Down syndrome.

Figure 4 shows a scatter-plot of age in years by verbal mental age, for participants with Down syndrome and those intended to be the verbal mental age control group. It shows that, despite recruiting a sample of younger non-disabled children to try to match for verbal age, there was little overlap between the two groups. In addition, when the verbal mental age scores of participants with Down syndrome were examined it was apparent that the

younger and older chronological age groups did not form two distinct verbal mental age groups. Instead, there was a large overlap in the verbal mental age scores of the two age groups and both groups had low scores on the BPVS-II.



The mean BPVS-II verbal mental age achieved by those in the Down syndrome group ( $M=5.05$ ,  $SD=1.77$ ) was lower than that for the non-disabled participants ( $M=7.77$ ,  $SD=1.57$ ). This difference was significant ( $t(51) = -5.87$ ,  $p < .001$ , two-tailed). Therefore, the two groups were not matched according to verbal mental age and the intention of having such a control group abandoned. Figure 5 illustrates the difference in mean BPVS-II verbal mental age between the two groups of participants.



An alternative method of controlling for verbal mental age may have been to use a statistical technique, such as Analysis of Covariance. However, this type of analysis was deemed inappropriate due to the small and uneven sample sizes in this investigation (Mayers, 2013). In addition, the BPVS-II scores were not normally distributed across groups and therefore violated one of the key assumptions of this test ( $D(95) = 0.12$ ,  $p = .002$ ). The control group design was used because it is consistent with convention in developmental psychology.

Since it did not prove possible to match a group of non-disabled participants with those with Down syndrome on verbal mental age, non-disabled participants were instead split into three chronological age groups. Despite not being matched on verbal mental age, the youngest group of non-disabled participants was considered to represent a useful comparison group, in the sense that they were children at an earlier developmental stage. This means that younger non-disabled participants had less social experience than all other participants and were closer to those in the Down syndrome group in terms of cognitive development. Participant groups and developmental details are shown in table 21 below.

**Table 21: Participant numbers and developmental information**

Disability group	Age group	N (girls)	Mean age (SD)	Mean VMA (SD)
DS	8.00-12.12	10 (4)	10.55 (1.34)	4.53 (1.65)
	13.00-17.12	18 (14)	15.03 (1.23)	5.35 (1.83)
	All	28 (18)	13.43 (2.52)	5.05 (1.78)
ND	5.00-7.12	14 (6)	6.21 (.96)	7.26 (1.42)
	8.00-12.12	27 (14)	10.24 (1.29)	10.17 (2.31)
	13.00-17.12	26 (14)	14.29 (1.27)	12.05 (1.58)
	All	67 (34)	10.97 (3.29)	10.29 (2.57)

Participants with Down syndrome comprised two age groups. There were 10 in a younger age group (mean age= 10.55) and 18 in an older age group (mean age= 15.03). Participants with no disability formed three age groups. There were 14 participants aged 5 years to 7 years and 12 months. The next group comprised a chronological age matched control group for the younger group of participants with Down syndrome (mean age= 10.24) and the next group a chronological age matched control group for the older group of participants with Down syndrome (mean age= 14.29).

As may be seen in table 21, there were roughly equal proportions of males and females in each disability group. The schools that children attended varied in terms of the socio-demographic status of the communities in which they were situated. The non-disabled children came from primary and secondary schools that served a range of communities, one was particularly affluent while others resided in more deprived areas of Glasgow. The areas in which the MLN schools were situated also varied. However, it should be noted that it is likely that the communities in which MLN schools are situated are less representative of the socio-demographic status of the families of pupils who go there, since pupils with disabilities tend to travel further to go to school.

## 4.4 Ethical approval

Ethical approval was granted from the University of Glasgow Ethics committee. The letter of approval may be found in Appendix A.

## 4.5 Recruitment

The first step taken was to gain permission from Glasgow City Council to approach school head teachers about the research. To recruit children with Down syndrome, contact was



made with the head teachers of four Moderate Learning Needs (MLN) secondary schools and four MLN primary schools by telephone. During the telephone calls, the researcher briefly outlined the aims and planned procedure for the study. Further information was then provided via email, and face to face meetings were arranged to discuss the project. All of the head teachers responded positively to the study. School administrative teams then sent letters and study information sheet to the parents of children with Down syndrome. There were 27 pupils with Down syndrome across the eight schools and 13 consent forms were returned.

As a result of the low response rate, recruitment continued over the following nine months as participants were sought from schools further afield than Glasgow and other potential means of contacting families were explored. Applications were made to a further seven local authorities in the West of Scotland. This process proved to be arduous but permission was finally granted by all but one local authority. Of the 12 schools approached, 8 head teachers were keen to be involved. Of the 8 schools who distributed study information to parents, four later reported that none of the consent forms had been returned. Therefore, as a result of the extended recruitment phase, data were collected from a further four schools in the West of Scotland.

The recruitment of participants from schools was a long and difficult process. The reason for the poor response rates to the letters sent out to parents was probably due to a number of factors. It is likely that some forms were lost en route to the family home. In addition, the many demands on parents' time probably resulted in consent forms being forgotten about. However, teachers also voiced their opinion as to why some parents may not have felt comfortable with the nature of this particular research study and had made a deliberate decision to withhold permission for their child to be involved. The teachers' view tended to be that parents had not come to terms with the fact their child had Down syndrome and that families would be worried that the research could provoke some awareness or understanding that their child was not ready to deal with.

Another means of reaching children with Down syndrome was through contact with local social and support groups run by the voluntary sector. Social group coordinators kindly distributed the study information to young people's parents. A stamped addressed envelope was provided so that parents could return their consent form and contact information directly to the researcher, if they wished their child to take part in the study. The

organisation Down Syndrome Scotland posted an advert for the study on their website, inviting parents to contact the researcher directly for further information. These approaches were met with some success and three children were recruited this way.

Children with no disability were recruited through mainstream primary and secondary schools in Glasgow. Ten Glasgow mainstream primary schools and five mainstream secondary schools were approached about the research. Data was collected from three Primary schools and three Secondary schools. Seven primary schools and two secondary schools declined to be involved, because they had already made commitments to other researchers or had other constraints on their time.

## **4.6 General procedure**

Consent was first obtained from children's parents. Approximately a week before the commencement of the study, the researcher paid an initial visit to the school to be introduced to the participants. The aim of this visit was to familiarise the children with the researcher to help them feel more comfortable when taking part in the research. These preparatory visits also allowed the researcher to become aware of any potential communication difficulties the participants had, thereby enabling her to communicate with the children more effectively during data collection. Finally, the visit helped to ensure that the children wished to consent to participate in the study. During her visit the researcher briefly explained her role as a researcher, the aims of the research and the procedure it would follow, thus giving children time to consider the study information in advance of the research proper.

On the day of the study, the researcher was allocated a room in the school by the head teacher that was quiet and free from distractions. Children were invited to join her on an individual basis. The researcher first asked the child if they remembered who she (the researcher) was and engaged in some light conversation with them. The child was then reminded of the study and asked if they would like to take part. It was ensured that each child was aware of what the study involved for them, that they were under no obligation to take part and that they could end their participation at any time. None of the children declined to participate.

Sitting next to the child, the researcher led them through three tasks that involved looking at photographs and pictures. Participants also completed the British Picture Vocabulary Scale II (BPVS-II; Dunn et al., 1997) for matching purposes.

Where the child was not recruited through a school, they met with the researcher at their home. Data was collected from three participants in this way.

## **4.7 Overview of measures**

The experimental component of the study comprised a series of three picture tasks. To aid the reader in following this chapter, a brief synopsis of each task and the research question they were used to address are provided below. However, each task will be dealt with in detail separately in forthcoming chapters. A final results chapter will discuss the findings from all three tasks.

### **4.7.1 Preference for Social Partners' task**

The aim in this task was to find out if participants showed a social preference to engage with others either with or without Down syndrome. Participants were presented with a forced choice between two photographs, one depicting a child with Down syndrome and another one without Down syndrome, and asked to indicate whose company they would prefer for six shared activities. The task used a 'posting box' game format such that participants indicated their preference by posting the chosen photograph into a box on which an illustration of each activity was attached.

### **4.7.2 Person Sorting task (part 1: other categorisation)**

This task was designed to assess participants' propensity to categorise photographs of other children according to whether or not they have Down syndrome. Participants were presented with two boxes that had a posting slot on the top. Attached to the front of one box was a photograph of a child with Down syndrome and on the other a photograph of a child with no disability. Participants were handed eight photographs of children one at a time, four of whom had Down syndrome and four who did not, and invited to put each photograph in the box they thought it belonged in.

### **4.7.3 Person Sorting task (part 2: self-identification)**

This task was an extension of the previous one. The aim was to find out if participants identified themselves as similar to the photographed child with Down syndrome or without Down syndrome. Participants were given a self-portrait photograph and after self recognition was checked, they were invited to put it into one of the boxes described above.

### **4.7.4 Adjective Attribution task (other and self)**

This task had two related aims. The first aim was to find out if children hold ideas about others with Down syndrome in line with social stereotypes of Down syndrome. The second aim was to find out how they viewed themselves in relation to these ideas. Participants were shown pairs of pictures that illustrated polar opposites of simple phrases used to describe people. Each pair of illustrations was presented one at a time and with the two illustrations placed on a separate post box. Participants were then shown three photographs in succession. One was of a child with Down syndrome, another of a child without Down syndrome and the final one was a self-portrait photograph. Participants were asked to post each photograph into the box with the illustration that best described the person.

### **4.7.5 The British Picture Vocabulary Scale II (Dunn et al., 1997)**

The British Picture Vocabulary Scale II (BPVS-II) is an updated version of the original BPVS. Good reliability is reported in the manual (median Cronbach's alpha of 0.93, median split-half of 0.86), and the validity of this version is assumed since it is derived from the previous version (Dunn et al., 1997). The BPVS-II provides a score that can be converted into an approximate verbal mental age using tables in the assessment manual. The efficacy of the scale in providing mental age equivalent scores in young people with Down syndrome has been demonstrated (Glenn and Cunningham, 2005). The BPVS-II covers a developmental age range from 2 to 16 years.

The assessment involves the participant being presented with a plate showing four black and white pictures. The child is then told a word and is asked to select which of the four pictures best represents the meaning of that word. The difficulty of the words gradually increases as the test progresses. A Verbal Mental Age is derived from the manual. The BPVS-II is commonly used with people with intellectual disabilities because it is easy to

administer and does not require speech (participants can respond simply by pointing) and is generally enjoyed by children and young people.

# **Chapter 5: Results of Experimental Studies**

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## **5.1 Preference for Social Partners' task**

In this chapter, the purpose of the 'preference for social partners' task will be explained and the hypotheses outlined. The method will then be described. Finally, the results will be reported and the chapter will end with a short discussion of the findings.

### **5.1.1 Purpose of task**

The purpose of this task was to find out if children show a positive or negative attitude towards interacting with others with Down syndrome. This was done by asking children about their preferred partners' for six social activities, when asked to choose between photographs of children with Down syndrome and photographs of children with no disability.

### **5.1.2 Hypotheses**

It was recognised that previous literature could support opposing hypotheses regarding the attitudes held by children with Down syndrome about engaging in activities with other children with Down syndrome. However, based on the research by Cooney et al. (2006) and Cunningham et al. (2000), it may be hypothesised that participants with Down syndrome would show a preference to interact with non-disabled children, just like their peers with no disability. This is because Cooney et al. and Cunningham et al. reported that young people with intellectual disabilities were aware of their disability and experienced stigmatised treatment. Based on the premise that stigma is pervasive in society and therefore that it is likely that all children would become sensitive to the stigma associated with disability, for the present investigation it was hypothesised that participants with Down syndrome and those with no disability would both show a preference to interact with children with no disability.

With regards to age group, it was hypothesised that older participants would show more bias towards interacting with non-disabled children compared to younger participants. This hypothesis was based on the assumption that older participants would have had more social experience and therefore more opportunity to become aware of the stigma attached to Down syndrome.

On the basis of the above hypotheses, the following predictions were made:

- i. Participants with Down syndrome will show a preference towards sharing pictured activities with photographs of children with no disability.
- ii. Participants with no disability the same age as participants with Down syndrome will show a preference towards sharing pictured activities with photographs of children with no disability.
- iii. Participants with no disability younger than participants with Down syndrome will show a preference towards sharing pictured activities with photographs of children with no disability.
- iv. Older participants will show more preference towards sharing pictured activities with photographs of children with no disability compared with younger participants.

### **5.1.3 Task materials and procedure**

Participants were asked about their preference for partners in six shared activities. The activities were: 'play with in the playground', 'sit next to in class', 'sit next to at lunch time', 'have in your team for a game', 'help you with your school work' and 'invite home to play'. The activities were represented by laminated colour illustrations. Each illustration measured 10 cm x 10 cm. The illustrations are shown in figure 6 below.



**Figure 6: Illustrations for Preference for Social Partners' task**

From top left, 'play with in the play ground', 'sit next to in class', 'sit next to at lunch', 'pick for your team in a game', 'help you with school work', 'invite home'.



The activity cards were presented one at a time on the front of a box using Velcro. The box measured H 13 cm x W 15.5 cm x D 15.5 cm and had a 'posting' slot on the top. For each activity, participants were presented with two laminated colour photographs, one showing a child with Down syndrome and one a child with no disability (both the same gender as the participant). The photograph pairs were placed directly in front of the posting box, side by side. Participants were first invited to talk about each pictured activity in order to establish that they understood what was being depicted. Then participants were asked to choose their preferred partner for each activity by posting one of the two photographs through the slot on the top of the box.

There were twelve photograph pairs in total. Six pairs comprised girls with Down syndrome and girls with no disability, and six pairs represented boys with Down syndrome and boys with no disability. For each activity, the position of the Down syndrome photograph (left or right hand side relative to the child) was randomised.

The photographs depicted the head and shoulders of each child and showed each child looking directly at the camera with a happy facial expression. Each photograph measured 12 cm x 10 cm. Figure 7 shows the experimental set up for the Preference task, using the illustration for 'pick for your team in a game'.



**Figure 7: Experimental set-up for Preference for Social Partners' task**

The six activities were presented to participants in the order described above. Each activity was assigned its own photograph pair, which remained the same for all participants. The task took approximately 10-15 minutes to complete.

### **5.1.4 Analysis strategy**

First of all the frequency of participants' choice of each type of photograph was examined for each of the pictured activities separately. These frequencies may be found in table 23. It was found that all groups of participants chose the photographs of non-disabled children more than the photographs of children with Down syndrome, for every activity. Since there was no difference in response pattern across the pictured activities, the frequencies were aggregated by calculating a 'preference score' for each participant, for each photograph type. This score represented how many times out of six trials the photographs of children with Down syndrome had been chosen and how many times the photographs of non-disabled children had been chosen. Since the two photograph scores were mutually

exclusive, i.e. participants were given a forced choice between the two photograph types, analysis was carried out on the preference for the non-disabled photograph only. Statistical analyses were organised around the predictions outlined above. The first prediction was that participants with Down syndrome would show a preference towards sharing pictured activities with photographs of children with no disability. This was tested using the binomial test. Based on the fact that there were six trials in this task, in which participants made six choices between a photograph of a child with Down syndrome and a photograph of a child with no disability, a cut-off of  $>3$  was used to represent a preference for one photograph over the other above chance level. In a similar fashion, the second and third prediction that non-disabled participants would show a preference towards sharing activities with photographs of children with no disability was also tested using the binomial test.

The final prediction was that older participants would show a greater degree of preference towards sharing activities with photographs of children with no disability compared to the younger participants. Since this involved comparing the mean scores of the younger and older age groups, exploratory analyses were first carried out to discover if the preference scores met the assumptions of normal distribution and homogeneity of variance required for the use of parametric statistics. The Kolmogorov-Smirnov test showed that participants' preference for the non-disabled photographs score were significantly different from normal for all but one group. Levene's test of homogeneity of variance showed that variance was equal across age groups within each disability group. These statistics may be found in table 22.

**Table 22: Tests of normality and homogeneity of variance for Preference task scores, for participants in each disability and age group**

NB. Down syndrome (DS); Non-disabled (ND)

Group	Kolmogorov-Smirnov			Levene's test of homogeneity		
	Statistic	df	Sig	Statistic	df	Sig
DS 8.00-12.12	.217	10	.200	.100	1, 26	.755
DS 13.00-17.12	.300	18	.001			
ND 5.00-7.12	.329	13	.001	1.689	2, 63	.193
ND 8.00-12.12	.202	27	.006			
ND 13.00-17.12	.238	26	.001			

Thus, it was found that the data violated the assumption of normality. Consequently, the non-parametric Mann Whitney U test was used to test this prediction.

### 5.1.5 Descriptive analysis

Table 23 below shows the number of participants who chose each type of photograph for each of six pictured activities. They are displayed separately for participants in each disability and age group.

**Table 23: Preference shown by participants with Down syndrome and no disability for photographs of children with DS and ND across six social activities**

Disability and age group	Photo	Play with	Sit next to in class	Sit next to at lunch	Pick for team	Help with school	Invite home
DS 8.00-12.12 years (n=10)	DS	3	2	2	2	4	1
	ND	7	8	8	8	6	9
DS 13.00-17.12 years (n=18)	DS	4	2	2	3	2	5
	ND	14	16	16	15	16	13
DS Total ( n=28)	DS	7	4	4	5	6	6
	ND	21	24	24	23	22	22
ND 5.00-7.12 years ( n=13a)	DS	1	3	0	2	2	1
	ND	12	10	13	11	11	12
ND 8.00-12.12 years (n=27)	DS	9	11	7	5	10	8
	ND	18	16	20	22	17	19
ND 13.00-17.17 years (n=26)	DS	8	10	7	6	5	7
	ND	18	16	19	20	21	19
ND Total (n= 66)	DS	12	24	14	13	17	16
	ND	32	42	52	53	49	50

a. In the no disability group there is one missing participant (one child looked very uncomfortable and did not want to complete the task).

Table 23 shows that across all the pictured activities participants were more likely to choose the photographs of non-disabled children than photographs of children with Down syndrome. Consequently, descriptive analysis was carried out on the total number of times each type of photograph was chosen across the six social activities. A preference score was calculated for the Down syndrome and non-disabled photographs (the highest possible

preference score for a photograph type being 6). Table 24 shows the median number of times participants in each disability and age group indicated a preference to share an activity with a photographed child with Down syndrome (DS) and without Down syndrome (ND).

**Table 24: Median preference score for each photograph type, by disability and age group**

Disability group	Age group	N	Median (range) number of times each photograph chosen	
			DS photo	ND photo
DS	8.00-12.12	10	1.00 (0-4)	5 (2-6)
	13.00-17.12	18	0.5 (0-3)	5.5 (3-6)
ND	5.00-7.12	13	0 (0-2)	6 (4-6)
	8.00-12.12	27	2 (0-6)	4 (0-6)
	13.00-17.12	26	1.5 (0-5)	4.5 (1-6)

The descriptive statistics in table 24 show that participants in all groups were more likely to choose the photographs of children with no disability to share six pictured activities with. There was minimal effect of age in both disability groups, although the youngest participants in the non-disabled group were less likely to choose the Down syndrome photograph than older participants.

### 5.1.6 Hypothesis testing

#### *Preference shown by participants with Down syndrome*

The binomial test was used to test the hypothesis that participants with Down syndrome would be significantly more likely to choose to share activities with the non-disabled photographed children.

A cut off point of  $>3/6$  was chosen for the preference for the non-disabled photographs across six activities because this represented the preference shown by participants above chance level. It was found that 23 of 28 participants with Down syndrome preferred the non-disabled photographs. The binomial test indicated this proportion was significantly different from chance ( $p=.001$ , 2 tailed). Therefore, the first hypothesis was supported.

*Preference shown by participants with no disability matched on chronological age*

For participants with no disability of the same chronological age as participants with Down syndrome, 39 out of 53 preferred the photographs of non-disabled children above chance level, and this is also significant ( $p=.001$ , 2 tailed). Therefore, the second hypothesis was supported.

*Preference shown by younger participants with no disability*

All participants with no disability who were younger in age to participants with Down syndrome preferred the photographs of children with no disability above chance level (13/13 participants). Therefore, the third hypothesis was also supported.

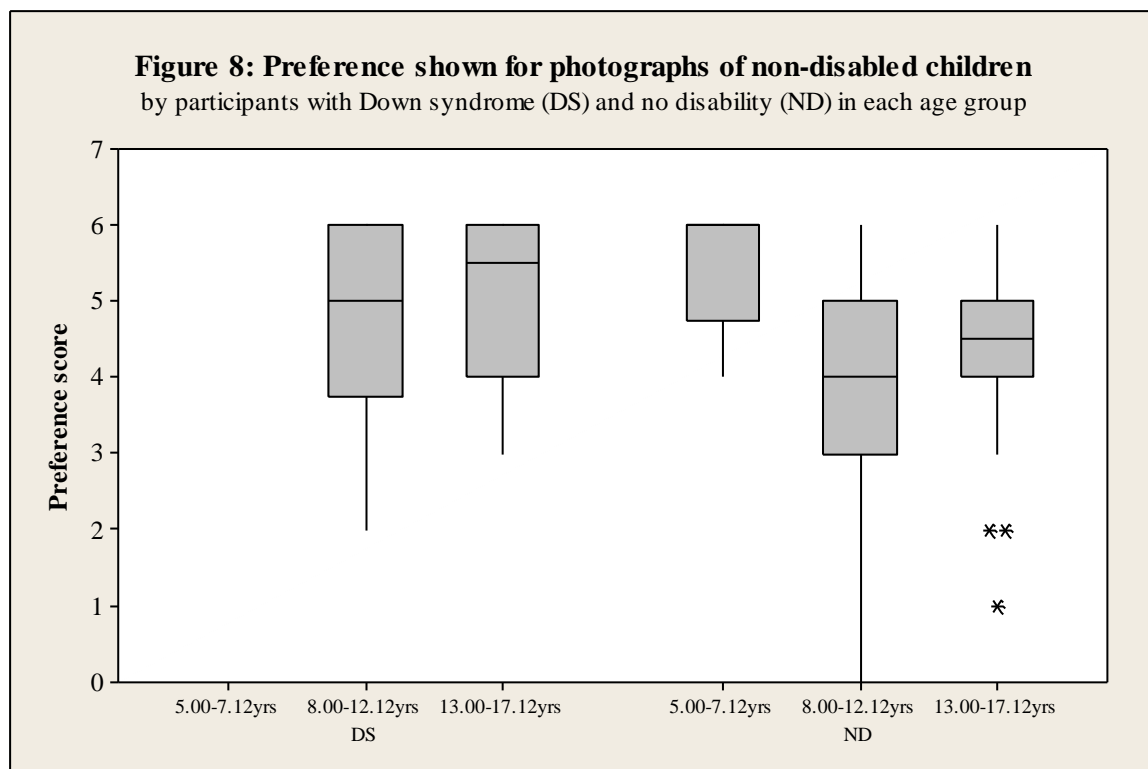
*Difference in preference shown between age groups of participants with Down syndrome*

A Mann-Whitney U test was used to find out if older participants with Down syndrome were more likely to prefer the non-disabled photographs than younger ones. The median number of times participants in the younger and older age groups preferred the non-disabled photographs was 5 (range= 2-6) and 5.5 (range= 3-6), respectively. The Mann Whitney U test confirmed that there was not a significant difference in preference for the non-disabled photographs shown by participants with Down syndrome ( $U (n=10, n= 18) = 73.5, p=.215, 1 \text{ tailed}, r = -.16$ ).

*Difference between preference shown by three age groups of non-disabled participants*

There were three age groups of non-disabled participants in total. The first group were younger than participants with Down syndrome (aged 5 to 7.12 years old), the second group were the same age as the younger group of participants with Down syndrome (aged 8 to 12.12 years old) and the third group were the same age as the older group of participants with Down syndrome (aged 13 to 17.12 years old). A Kruskal-Wallis test was used to find out if older participants with no disability were more likely to prefer the non-disabled photographs compared to younger ones. This showed that there was a significant difference between the preference scores of the three groups ( $H (df =2) = 7.53, p = .021$ ). Three Mann-Whitney U tests were then used to determine where the difference lay among the three groups. These showed that there was not a significant difference between the preference scores of those in the second and third age groups ( $U (n=27, n=26) = 324, p=.627, 2 \text{ tailed}$ ). However, there was a significant difference in preference scores between the first age group and the second age group ( $U (n=13, n=27) = 89.5, p=.005, 1 \text{ tailed}$ ) and

the first age group and the third age group ( $U(n=13, n=26) = 92, p=.01, 1$  tailed). The medians suggest that the participants aged 5 to 7.12 years old were more likely than those both of the older age groups to prefer the non-disabled photographs. The box plot in figure 8 illustrates the preference for the non-disabled photograph shown by participants in both disability groups and all age groups.

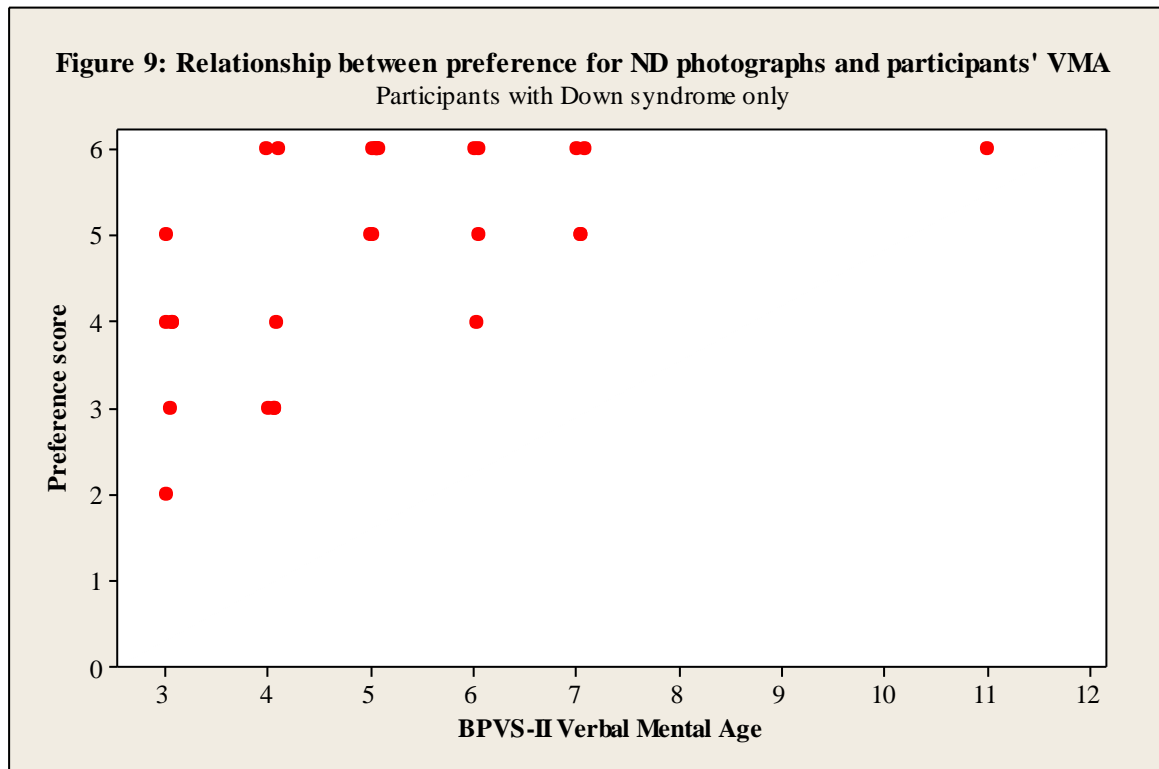


### 5.1.7 Post hoc analysis

While all groups of participants showed a clear preference for the photographed children with no disability, it was also apparent that a minority of participants did not. The researcher sought to explore the potential differences between these participants and the majority, and factors that may explain their differing responses. Based on the previous literature (Cunningham and Glenn, 2001), it was reasoned that verbal mental age may be a contributory factor.

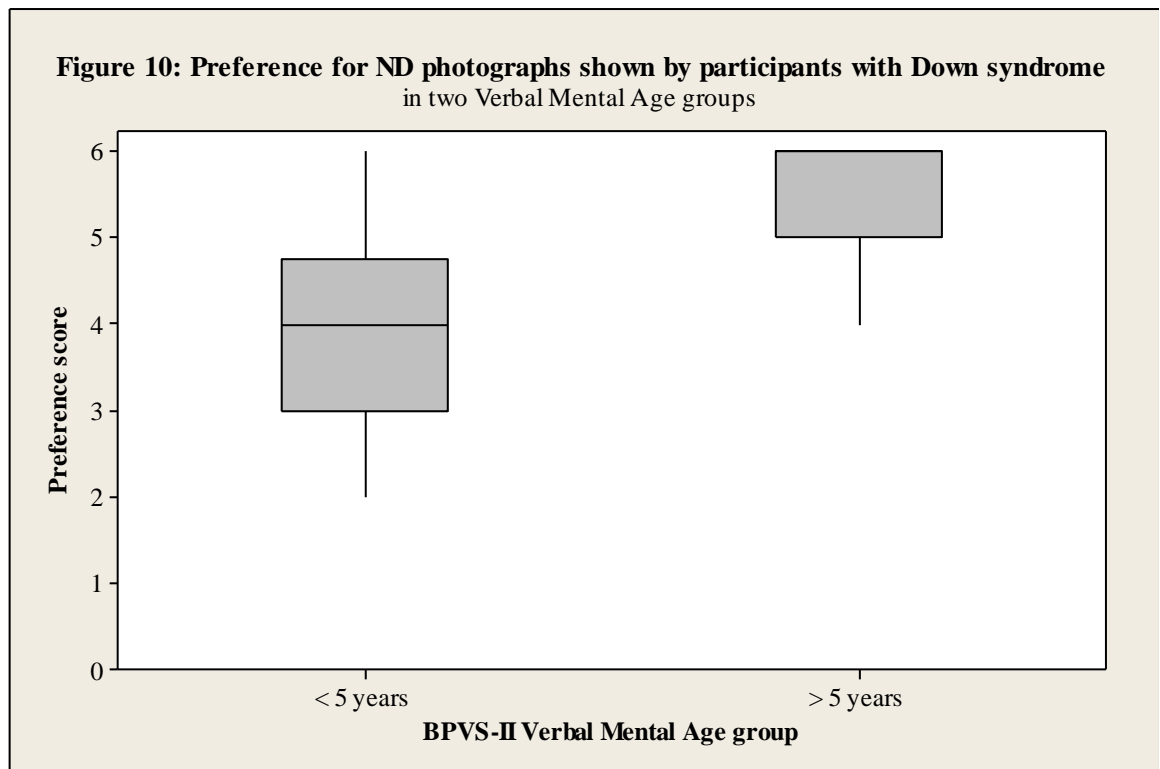
A Kendall's Tau correlation was performed on BPVS-II scores and preference scores for the photographs of children with no disability, for the participants with Down syndrome. The Kendall Tau correlation coefficient was deemed appropriate due to the small sample size (Field, 2005, p. 131). A significant positive correlation was found between participants' BPVS-II score and preference for the non-disabled photographs score ( $\tau(n=28) = .458, p = .002, 2$  tailed). Therefore, this suggested that as participants' verbal mental age increased, their preference score for the non-disabled photographs also

increased. Figure 9 shows the relationship between participants' verbal mental age and preference to share activities with the non-disabled photographs.



To explore this further, participants with Down syndrome were split into two groups; those with scores on the BPVS-II indicating a verbal mental age < 5 years old and those scoring above this level. A Mann-Whitney U test was then performed to find out if the preference for the photographed children with Down syndrome shown by these two groups differed. The verbal mental age < 5 years old group (n=12) had a median preference for the Down syndrome photograph score of 2 (range 0-4). The remaining participants (n=16) had a median preference score of 0 (range= 0-2). A Mann Whitney U test showed that those with a verbal mental age below 5 years were significantly more likely to choose the photographed children with Down syndrome compared to the participants whose verbal mental age was above 5 years old ( $U= 27.5$ ,  $p=.001$ , 2 tailed,  $r= -0.6$ ). Figure 10 below illustrates the different responses by these groups.





A correlation was also carried out on the BPVS-II scores of participants with no disability and their preference for the non-disabled photographs. This revealed a marginally significant negative correlation ( $\rho$  ( $n=66$ ) =  $-.249$ ,  $p = .044$ , 2 tailed). This indicates that, with increasing verbal mental age, participants in this group were more likely to choose the Down syndrome photographs.

A correlation was also carried out on the BPVS-II scores and preference scores of participants with no disability in the younger group only and this was not significant ( $\tau$  ( $n=13$ ) =  $.000$ ,  $p = 1$ ). This result probably reflected the lack of variance in these participants' responses.

Participants with Down syndrome in the younger age group showed a slightly greater preference to share activities with the non-disabled photographs than those in the older age group. Although this group difference was not statistically significant, a potential relationship between chronological age and preference for the non-disabled photographs was explored further using a correlation analysis. This was not significant ( $\tau$  ( $n=28$ ) =  $.108$ ,  $p = .465$ , 2 tailed).

### 5.1.8 Discussion

Participants' responses showed no difference according to pictured activity, instead they showed a preference to share activities with the children with no disability for all pictured activities.

The results show that participants with Down syndrome chose the photographed children with no disability to share pictured activities with more often than photographed children with Down syndrome. Participants' degree of preference was similar in both the younger and older age groups. The results from the non-disabled participants showed that overall that they also indicated a preference to interact with the non-disabled children. Participants in the youngest age group showed significantly greater preference for the non-disabled children than those in both of the older age groups.

These findings suggest that at the time of testing, all children had considerable awareness of the stigma attached to Down syndrome. Thus, it may be tentatively suggested that both the ability and experience necessary to make children aware of such social views was already well in place by the time of the study. This is consistent with previous findings about young people's awareness of stigmatised treatment (Cooney et al., 2006), although there have been no previous findings with children as young as 8 years of age.

There were however participants who did choose the photographed children with Down syndrome, on at least some occasions. Post hoc analyses were carried out to explore the potential mechanisms behind this. Previous research by Cunningham et al. (2000) had emphasised the role that verbal mental age plays in awareness of disability. Thus, the relationship between verbal mental age and participants responses in this study was investigated.

Firstly, focussing on the participants with Down syndrome, a significant correlation showed that a lower verbal mental age was associated with a greater likelihood of choosing the photographed children with Down syndrome. This finding suggests that higher verbal mental age was associated with greater awareness of stigma, and hence a lesser wish to share activities with children who have Down syndrome. The verbal mental age of 5 years old was found to be significant in understanding the social category of Down syndrome in the study by Cunningham et al. (2000). For this reason, participants with Down syndrome were split into two groups; those whose scores on the BPVS-II had indicated they had a verbal mental age of below 5 years or above 5 years old. The preference shown by these

two groups was then compared. This analysis corroborated that verbal mental age played a role in the preference shown by participants with Down syndrome, since the group with the lower verbal mental ages were more likely than those with verbal mental ages above 5 years to choose the photographed children with Down syndrome.

The relationship between performance on the BPVS-II and preference for the non-disabled photograph in the group of participants with no disability showed the reverse pattern. As BPVS-II score increased the likelihood of them choosing the Down syndrome photographs increased. Although speculative, observation of participants by the researcher during this task suggested that an increasing awareness of social desirability may have played a role. Participants looked uncomfortable at being asked to choose between children with and without Down syndrome and one young girl seemed so uncomfortable that the task was discontinued.

The comments made by participants' aged 13 to 17.12 years suggested they had a strong sense of fairness and that it was socially unacceptable to exclude children with disabilities. Fourteen participants in this group expressed during the task that, 'they wouldn't mind' or that they would 'choose both' or 'either'. Others said that they 'felt bad' and that 'they were not that kind of person'. These participants expressed a strong desire to respond in a socially desirable way, and to be seen as 'a good person'. Whether this reflects how the children behave in real life is a different matter, but it does show that openly discriminatory attitudes towards people with Down syndrome are regarded as socially unacceptable and this is consistent with attitudes towards other minority groups (Antonak and Livench, 2000).

In sum, all participants showed a strong preference towards interacting with the photographed children with no disability compared to those with Down syndrome. However, there was some evidence that verbal mental age had a role to play in a small proportion of responses favouring the photographs of children with Down syndrome in the Down syndrome group and that social desirability played a role in similar responses from non-disabled participants.

## **5.2 Person Sorting task**

### **5.2.1 Purpose of task**

The purpose of this task was to assess participants' propensity to categorise others according to the social category of Down syndrome.

### 5.2.2 Hypotheses

Based on the premise that young people with and without Down syndrome occupy the same social environment and will therefore be similarly aware of Down syndrome as a social category, it was hypothesised that both groups of participants would sort the photographs according to whether the children had Down syndrome or not. With regards to age group, it was hypothesised that older participants would show a greater propensity to sort the photographs according to Down syndrome than younger participants. This hypothesis was based on the assumption that the saliency of Down syndrome as a social sorting criterion would increase with age and social experience.

On the basis of the above hypotheses, the following predictions were made regarding participants responses on the sorting task:

- i. Participants with Down syndrome will show a propensity to sort the photographs according to whether the depicted individuals have Down syndrome or not above chance level.
- ii. Participants with no disability the same age as participants with Down syndrome will show a propensity to sort the photographs according to whether the depicted individuals have Down syndrome or not above chance level.
- iii. Participants with no disability younger than participants with Down syndrome will show a propensity to sort the photographs according to whether the depicted individuals have Down syndrome or not above chance level.
- iv. Older participants will show a greater propensity to sort the photographs according to whether the depicted individuals have Down syndrome or not than younger participants.

### 5.2.3 Task materials and procedure

The task began with the researcher introducing the child to two rectangular boxes, each with a slot on the top for posting pictures. On the front vertical side of each box, a picture was attached using Velcro; one depicted a red object, the other a blue one. The child was asked to notice how these two pictures differed from one another. Next, the child was presented with 8 pictures of everyday objects, 4 red and 4 blue, one at a time. Participants were asked to post each one through the slot of the appropriate box, 'to go with' the

corresponding picture. The purpose of this short task was to check the child had the skills necessary to participate in the sorting task proper. Thus, if the child was unable to perform this task, they were given praise for their work, but their participation in the sorting task was ended at this stage. Participants were regarded as having 'passed' this task if they sorted 7 out of 8 pictures into the correct box.

In the sorting task proper, participants were presented with the same posting boxes as before but this time the researcher attached a photograph of a same age and gender child with Down syndrome to one box and a photograph of a same age and gender child with no disability to the other box. Participants were invited to look at each photograph. Participants were introduced to a selection of similar photographs of children (four of these had Down syndrome and four did not). They were told that some of the photographs belonged with the photograph on one box and some belonged with the photograph on the other box. Participants were then handed each of the eight photographs one at a time in a random order and invited to put it into the box with the photograph they thought it belonged with. Figure 8 shows the experimental set up for one trial of the Sorting task (having put the first photograph in one of the boxes, the participant was shown a further seven photographs; 4 of boys with Down syndrome and 3 with no disability, in a random order).



**Figure 11: Experimental set up for Person Sorting task**

### **5.2.4 Analysis strategy**

Participants were given a 'sorting score' which represented how many of the photographs they categorised according to Down syndrome. Since there were eight photographs in total, the highest possible sorting score was eight.

First of all, descriptive analysis was carried out to explore the obtained data. Descriptive data is shown in table 26. Statistical analysis was then carried out and it was organised around the predictions outlined above. The first prediction was that participants with Down syndrome would sort the photographs according to whether the children depicted had Down syndrome or not, above chance level. Since there were eight trials in which participants sorted four photographs of children with Down syndrome and four photographs of children with no disability, a sorting score of greater than 4 was regarded as being above chance level. The binomial test was used to test the prediction using a cut-off of  $> 4$ . Similarly, the second and third hypotheses that participants with no disability

matched on chronological age and those in the younger age group would sort the photographs according to Down syndrome were analysed using the binomial test using the > 4 sorting score cut-off point.

The final prediction was that older participants would show a greater propensity to sort the photographs according to Down syndrome than younger participants. Since this involved comparing the mean sorting scores of the younger and older age groups, exploratory analyses were first carried out to determine if the sorting scores for each age group and disability group met the assumptions of normality and homogeneity of variance for parametric analysis.

**Table 25: Tests of normality and homogeneity of variance for sorting scores of participants in each disability and age group**

Group	Kolmogorov-Smirnov			Levene's test of homogeneity		
	Statistic	df	Sig	Statistic	df	Sig
DS 8.00-12.12	.193	10	.200	.051	1, 26	.824
DS 13.00-17.12	.159	18	.200			
ND 5.00-7.12	.168	14	.200	1.904	2, 64	.157
ND 8.00-12.12	.285	27	.001			
ND 13.00-17.12	.282	26	.001			

As shown in table 25, the scores of two age groups of participants with no disability violated the assumption of normality. Therefore, non-parametric tests were employed. The median sorting scores of younger and older participants with Down syndrome were then compared using the Mann-Whitney U test and the median sorting scores of the three age groups of participants with no disability compared using the Kruskal Wallis test. The exact significance test was utilised due to small sample sizes, as recommended by Field (2005).

Since this study was predominantly exploratory, it was important to ensure as far as possible that it was sensitive to potential group differences. Therefore, in order to reduce the risk that real differences would go undetected (making a type II error), it was decided that formal correction procedures for carrying out multiple comparisons would not be conducted (Perneger, 1998).

## 5.2.5 Descriptive analysis

Table 26 shows the median number of times participants in each disability and age group sorted eight photographs according to Down syndrome.

**Table 26: Median sorting scores by disability and age group (max. score 8)**

Disability group	Age group	N	Median (range) sorting score
DS	8.00-12.12	10	5 (1-8)
	13.00-17.12	18	4.5 (2-8)
ND	5.00-7.12	14	6 (4-8)
	8.00-12.12	27	8 (3-8)
	13.00-17.12	26	7.5 (4-8)

In order to gain a fuller appreciation of the obtained data, it is also represented graphically in figure 12.

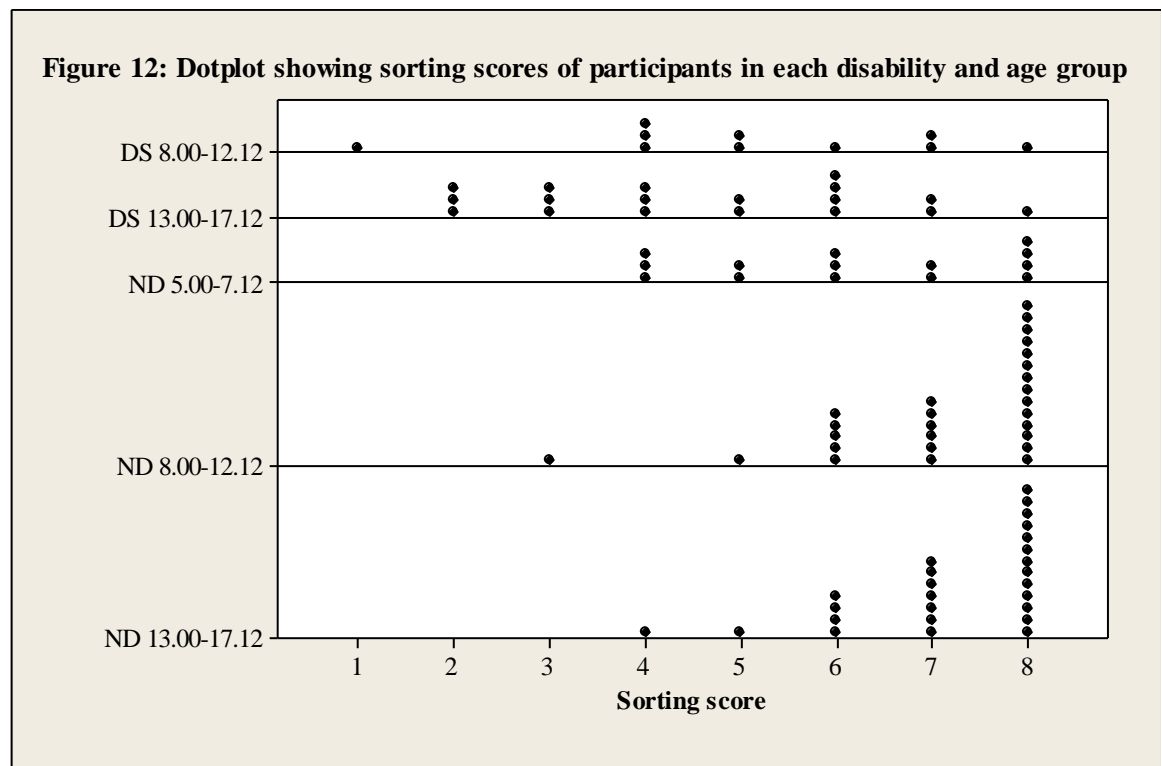


Figure 12 illustrates the sorting performance demonstrated by participants in each disability and age group. The spread of sorting scores from participants with Down syndrome in both age groups is large. However, the majority of those in the younger age



group sorted the photographs just above chance level, while those in the older group were more likely to sort below chance level. Participants with no disability in the youngest age group (5 years to 7 years 12 months old) showed a similar spread of scores to their peers with Down syndrome in the younger age group. That is, their scores tended to range from chance upwards. There was a considerable skew in the sorting task scores obtained from participants that were the same chronological age as those with Down syndrome, with the majority scoring at the ceiling level. A minority of outliers performed around chance level.

## 5.2.6 Hypothesis testing

### *Sorting of participants with Down syndrome*

It was hypothesised that participants with Down syndrome would sort the photographs according to whether the children had Down syndrome or not. Taking the cut-off point of a sorting score of  $>4/8$  as above chance level sorting, fifteen of 28 participants with Down syndrome sorted according to whether or not the photographs depicted children with Down syndrome, and the remaining 13 participants did not sort the photographs according to Down syndrome. The binomial test confirmed that this difference was not significant ( $p=.851$ , 2 tailed). Therefore, the first prediction was not supported.

### *Sorting of participants with no disability matched on chronological age*

It was hypothesised that participants with no disability would sort the photographs according to whether the children had Down syndrome or not. It was found that 51 out of 53 sorted the photographs according to Down syndrome above chance level ( $>4/8$ ). This is significant (binomial  $P=.001$ , 2 tailed). Therefore, the second hypothesis that participants with no disability would show a propensity to sort the photographs according to Down syndrome above chance was supported.

### *Sorting of younger participants with no disability*

It was hypothesised that the youngest participants with no disability would sort the photographs according to whether the children had Down syndrome or not. It was found that 11 out of 14 participants in this group sorted above chance level. This was close to significance (binomial,  $p=.057$ , 2 tailed). Given the small sample size, it may be reasonable to assume that a larger sample size would have offered clear support for the hypothesis.

*Sorting of two age groups of participants with Down syndrome*

It was hypothesised that older participants with Down syndrome would show a greater propensity to sort the photographs according to whether the depicted individuals have Down syndrome or not than younger participants. A Mann-Whitney U test demonstrated that the sorting scores of the younger and older age groups of participants with Down syndrome were not significantly different ( $U(n=10, n=18) = 75, p = .243, 1$  tailed). Therefore, this hypothesis was not supported.

*Sorting of three age groups of participants with no disability*

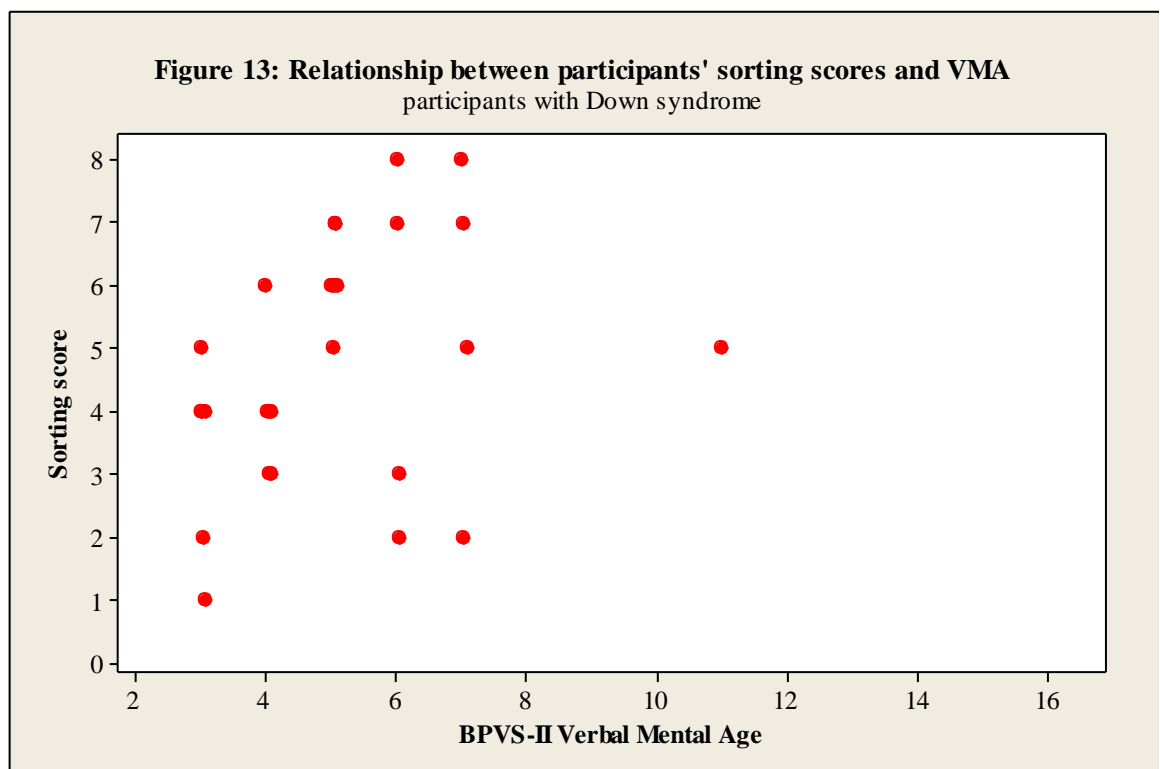
It was hypothesised that older participants with no disability would show a greater propensity to sort the photographs according to whether the depicted individuals have Down syndrome or not than younger participants. The Kruskal-Wallis test showed that there was a significant difference in the sorting scores of three age groups of participants with no disability ( $H(df=2) = 5.13, p = .02$ ). Three Mann-Whitney tests were then performed to find out where the difference lay. This showed that there was no difference in the sorting scores of the middle and older age group ( $U(n=27, n=26) = 350.5, p = .502, 1$  tailed). However, there was a significant difference between the sorting scores of both the young and middle age group ( $U(n=14, n=26) = 113.5, p = .022, 1$  tailed) and the younger and older age group ( $U(n=14, n=27) = 119.5, p = .022, 1$  tailed). Therefore, the hypothesis that participants in the older age group would sort the photographs with a greater degree of accuracy than younger participants was partially supported by participants with no disability.

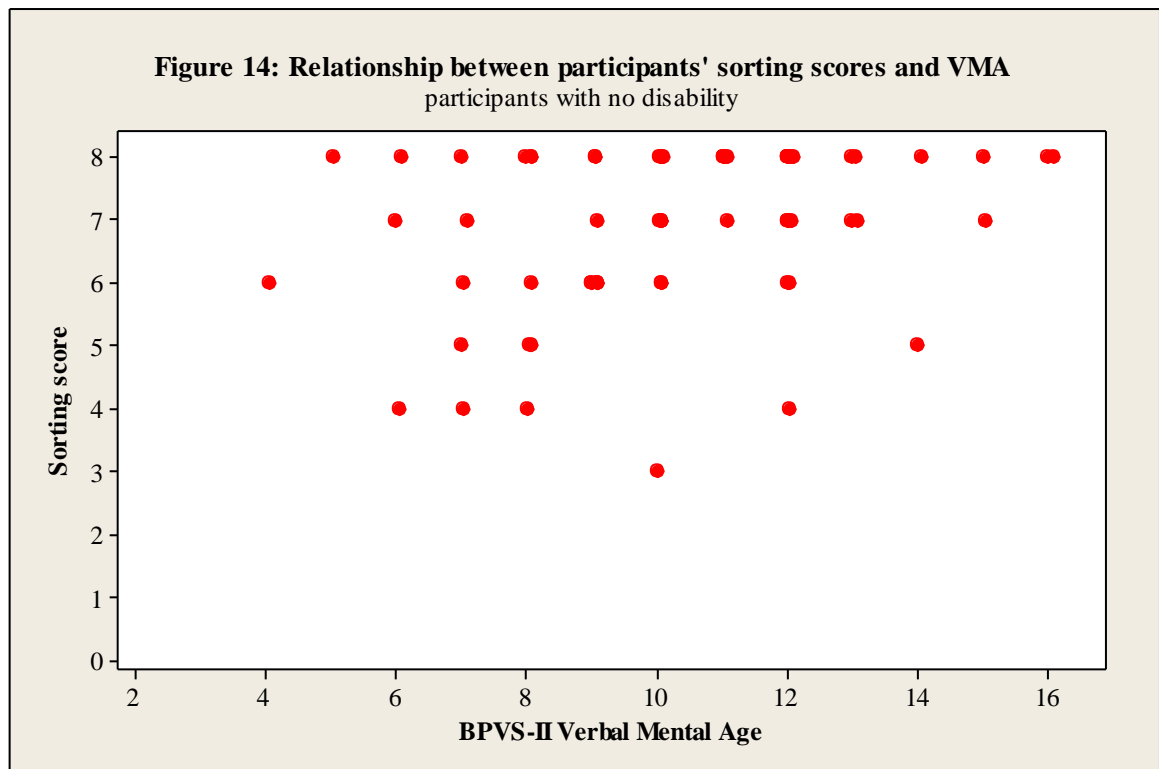
## 5.2.7 Post hoc analysis

Post hoc analysis centred on exploring possible explanations for the lack of sorting demonstrated by participants in the Down syndrome group. The study by Cunningham et al. (2000) suggested that verbal mental age is a critical factor in awareness of Down syndrome in young people with Down syndrome. In addition, the present study found that the sorting scores of a group of non-disabled participants who were aged 5 to 7.12 years old and had verbal mental ages closer to those in the Down syndrome group were comparable in terms of the broad range of scores obtained. Therefore, together, these findings indicated that verbal development level may have contributed to participants sorting performance.

First of all the relationship between verbal mental age and sorting performance was explored by correlating these two variables. Kendall's Tau correlation coefficient was selected due to the small sample and large number of tied ranks (Field, 2005, p. 131). For participants with Down syndrome, a significant positive correlation was found between sorting score and verbal mental age ( $\tau = .278$ ,  $n = 28$ ,  $p = .025$ , 1 tailed). For all participants with no disability ( $n = 67$ ), a significant positive correlation was found between sorting score and verbal mental age ( $\tau = .244$ ,  $p = .005$ , 1 tailed). The relationship between verbal mental age and sorting score may be seen in figures 13 and 14.

There was not a significant correlation between verbal mental age and sorting score for participants with no disability in the younger group only ( $\tau = (n = 14) = .217$ ,  $p = .310$ , 1 tailed).





Cunningham et al. (2000) reported that a verbal mental age of 5 above years old appeared to be the benchmark for an awareness of Down syndrome to develop in young people with Down syndrome. Based on their finding, participants with a verbal mental age below 5 years old were excluded from the analysis, in order to determine if the Down syndrome group continued to sort the photographs to lesser degree from the non-disabled group. This resulted in 12 participants with Down syndrome and 1 participant with no disability in the younger group being excluded from the following analysis. It was recognised that the small remaining participant numbers make the following analyses tentative. Table 27 shows the median sorting scores obtained by each participant group, having excluded participants whose verbal mental age was below 5 years old.

**Table 27: Median sorting scores by disability and age group excluding participants with a VMA below 5 years old (max. sorting score 8)**

Disability group	Age group	N	Median (range) sorting score
DS	8.00-12.12	4	7 (5-8)
	13.00-17.12	12	6 (2-8)
	Total	16	6 (2-8)
ND	5.00-7.12	13	6 (4-8)
	8.00-12.12	27	8 (3-8)
	13.00-17.12	26	7.5 (4-8)
	Total	66	7 (3-8)

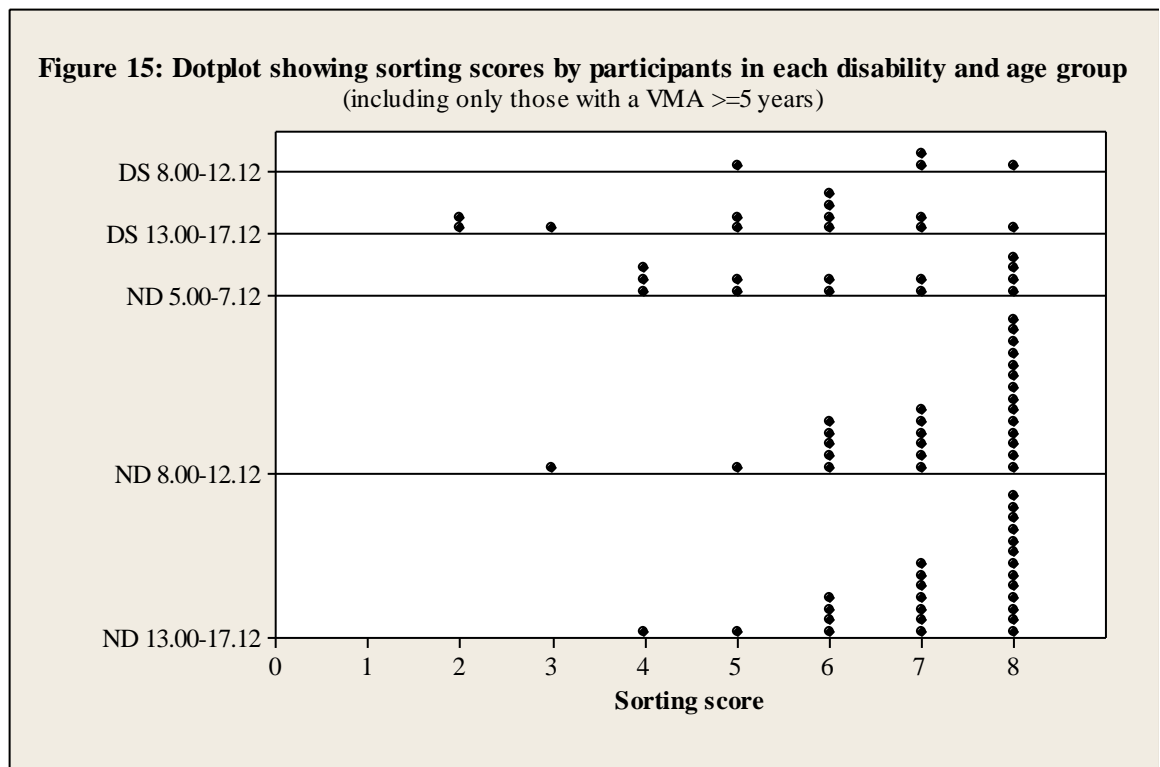


Figure 15 shows that by excluding the scores of participants with a verbal mental age below 5 years old the distribution of scores is changed slightly in the Down syndrome group. Participants who had some of the lowest sorting scores have been knocked out. This brings the scores of the Down syndrome group closer to those of the youngest group of non-disabled participants. In both the Down syndrome group and the youngest non-disabled group there continued to be considerable spread in scores, in the main from a chance score of 4 upwards.

Having excluded participants whose verbal mental age was below 5 years old, the binomial tests were re-run. These showed that taking the cut-off point of a sorting score of  $>4/8$  as above chance level sorting, 13 of 16 participants with Down syndrome sorted according to whether or not the photographs depicted children with Down syndrome, and the remaining 3 participants did not sort the photographs. The binomial test confirmed that this is significant ( $p = .021$ , 2 tailed). Similarly, for participants with no disability of the same chronological age, 51 out of 53 sorted the photographs according to Down syndrome above chance level. This is significant (binomial  $P = .001$ , 2 tailed). For participants with no disability of younger age, 10 out of 13 sorted the photographs above chance level. However, this was not significant, probably because the sample was small (binomial,  $p = .092$ , 2 tailed).

The relationship between verbal mental age and sorting score was also seen to disappear once those with a verbal mental age below 5 years old were excluded (ND youngest group:  $\tau = .240$ ,  $n = 13$ ,  $p = .142$ , 1 tailed; ND chronological age controls:  $\tau = .160$ ,  $n = 53$ ,  $p = .069$ , 1 tailed; Down syndrome group  $\tau = -.101$ ,  $n = 16$ ,  $p = .305$ , 1 tailed).

The age group effects remained the same in the refined data set. That is, there was not a significant difference in the scores of younger and older participants with Down syndrome ( $U(n=4, n=12) = 12.5$ ,  $p = .084$ , 1 tailed). The Kruskal Wallis demonstrated that there was a difference between the sorting scores of participants with no disability in three age groups ( $H(df=2) = 4.25$ ,  $p = .039$ ). Mann Whitney tests showed that the middle age group scored significantly higher than those in the youngest age group ( $U(n=13, n=27) = 115$ ,  $p = .034$ , 1 tailed) and that those in the oldest age group also scored significantly higher than those in the youngest age group ( $U(n=13, n=26) = 109.5$ ,  $p = .033$ , 1 tailed). There was not however any difference in sorting scores between those in the middle and older age groups ( $U(n=26, n=27) = 350.5$ ,  $p = .502$ , 1 tailed).

With regards the hypotheses in relation to the refined data set, only tentative conclusions may be drawn as a consequence of small participant numbers. The first hypothesis that participants with Down syndrome would sort the photographs according to whether or not they depicted children with Down syndrome above chance level was supported. The second hypothesis that participants with no disability of the same chronological age would also sort the photographs according to Down syndrome was clearly supported. The third hypothesis that participants with no disability of younger chronological age would sort the

photographs was only marginally supported (perhaps due to the small sample). Finally, the hypothesis that participants in the older age groups would have higher sorting scores than those in the younger age groups was not supported in participants with Down syndrome, but partially supported for participants with no disability. Participants with no disability aged 8 years to 17 years 12 months had significantly higher sorting scores than those aged 5 years to 7 years and 12 months old.

In order to find out if there was a significant difference between the sorting scores of participants with Down syndrome who had a verbal mental age below and above 5 years old, a Mann Whitney U test was carried out. This showed that there was a significant difference in the sorting scores of these two groups ( $U = (n=12, n=16) 36.5, p=.005, 2$  tailed). The median sorting score for those with a verbal mental age below 5 years old was 4 (mean= 3.67) and for those with a verbal mental age above 5 years old the median sorting score was 6 (mean= 5.63). Therefore, those with a verbal mental age above 5 years old were significantly more likely to sort the photographs according to Down syndrome.

It would seem then that verbal mental age may have been a factor in the poorer sorting performance of participants with Down syndrome and a verbal mental age above 5 years old appeared to particularly important. However, if one returns to examine the individual data plots on the scatter-graph in figure 13, it may be seen that while there is a visible trend of those with higher verbal mental age scores to sort more photographs according to Down syndrome, there was also a substantial number of participants who had higher verbal mental ages but sorted below chance level and a few participants who had low verbal mental ages and high sorting scores. Therefore, it may be simplistic to assert the only factor involved was verbal ability.

### **5.2.8 Discussion**

To summarise, using the full data set it was found that participants with Down syndrome did not sort the photographs according to Down syndrome. However, participants with no disability of the same chronological age sorted photographs at ceiling level. The performance of participants with no disability who were younger in age and had verbal ability closer to participants with Down syndrome sorted above chance level but their sorting was not as accurate as that of older non-disabled participants. The analysis also showed that the sorting scores of participants with Down syndrome were positively

correlated with verbal mental age, as were the sorting scores of non-disabled younger participants. Based on research conducted by Cunningham et al. (2000), the significance of a verbal mental age of 5 years old was explored. It was found that when participants whose verbal mental age was below 5 years old were excluded from the analysis, the proportion of those with Down syndrome who sorted the photographs above chance level increased. In addition, those with a verbal age above 5 years old sorted significantly more photographs according to Down syndrome than those with a verbal mental age below 5 years old. These findings suggested that verbal mental age, and in particular the verbal mental age of 5 years old, may have been a factor in performance on this task.

Verbal mental age is often taken as a good indicator of general cognitive developmental level (Cunningham et al. 2000). Therefore, the relationship between verbal mental age and sorting performance may suggest that children with Down syndrome with lower verbal mental ages, and particularly those with a verbal mental age below 5 years old, were less aware of Down syndrome because they were at an earlier cognitive developmental stage. This interpretation is consistent Cunningham et al.'s (2000) findings. Cunningham et al. (2000), asked young people with Down syndrome to put photographs of persons with Down syndrome and persons with no disability into two piles, and then to place their own photograph onto one of the piles. They found that the only young people with Down syndrome who demonstrated an awareness of Down syndrome had verbal mental ages above 5 years old. They argued that a verbal mental age of 5 years old reflects a cognitive developmental stage critical to one's self and other understanding in terms of Down syndrome and disability, and that this age fits with the developmental trajectory of self and social understanding found in typically developing children. However, to suggest that all of the participants in the present study whose verbal mental age was below 5 years old were not aware of Down syndrome contrasts with the results of the previous task. Although verbal mental age also appeared to be related to preference shown by participants, the majority of participants across all groups showed a preference for the non-disabled photographs above chance level. In other words, in contrast to the sorting task, participants with Down syndrome demonstrated a high degree of discrimination between photographs of children with and without Down syndrome in the preference task.

Another possible explanation of the findings is that verbal mental age was related to participants' sorting performance because greater cognitive ability was required to carry out or understand the task. The sorting task may have demanded greater cognitive ability than the previous preference task and it may have been that the ability required was beyond



some of the participants with Down syndrome and younger non-disabled participants. While the control sorting task of objects was intended to avoid this eventuality, it is possible that it was ineffective. Perhaps the sorting of everyday objects according to two colours was not equivalent to sorting the faces of individuals.

There are several ways in which the sorting task may have been more cognitively demanding than the other tasks. Firstly, in the preference task, children were shown photographs of children with and without Down syndrome for paired comparison. Presenting the photographs in pairs perhaps made the social category more salient and easier to identify. By contrast, in the sorting task, photographs of children with and without Down syndrome were presented one at a time. However, the photographs on the boxes continued to represent an exemplar from each group throughout the procedure, so that, in effect, participants were being asked to match each photograph they were handed to one of two photographs (one of a child with Down syndrome and one of a child without Down syndrome) that were open to view simultaneously. The process of matching to one of two alternatives may still have been more difficult than choosing between two options, as in the preference task.

It is also possible that the sorting task demanded greater verbal ability in order to understand the task. Therefore, it may be that participants with Down syndrome had greater difficulty understanding the task instructions and the range of their sorting scores reflected the fact that many participants were not sure what they were being asked to do. In contrast to the preference task, the sorting task did not involve colour illustrations to aid task comprehension.

Although there are plausible reasons why ability to do the task could have been an issue, it must also be emphasised that the task was chosen specifically because it should have been well within the capabilities of the participants. It was adapted from a task used by Weinraub (1984). She reported that the majority of children aged 36 months sorted at least 7 of 8 photographs according to gender. This suggests that comprehension of the task or ability to do the task per se was not the issue.

A further possibility is that for some participants with Down syndrome a failure to sort the photographs according to whether or not the photographs showed children with Down syndrome was not due to a lack of ability or awareness but was a deliberate choice they

made not to sort on the basis on this category. The individual data plots on the scatter-graph, illustrating the relationship between verbal mental age and sorting score (figure 12), show that while there was a visible trend of those with higher verbal mental age scores sorting more photographs according to Down syndrome, there was also a notable number of participants who had higher verbal mental ages but sorted below chance level and a few participants who had low verbal mental ages and high sorting scores. If participants were deliberately choosing to ignore the distinction between individuals with Down syndrome this could reflect either positive or negative underlying attitudes.

In conclusion, the meaning of the findings from the sorting task are far from clear and do not appear to reflect ability alone. Further reflection on the results of this task in relation to findings from all the experimental tasks might offer helpful insights. Therefore, the findings of the sorting task will be returned to in the final section of the results where all the experimental tasks will be discussed together.

## **5.3 Self-Identification task**

### **5.3.1 Purpose of task**

The purpose of this task was to find out if participants identified themselves as similar to a photograph of a child with Down syndrome or one of a child with no disability.

### **5.3.2 Hypotheses**

It was recognised that the previous research could support opposing hypotheses regarding whether participants with Down syndrome would self-identify with others with Down syndrome. However, based on the research by Cooney et al. (2006) and Norwich (1997), Norwich and Kelly (2004), Kelly and Norwich (2004), who reported that young people were aware of their intellectual disability, and studies by Cunningham et al. (2000) and Cunningham and Glenn (2004), in which it was reported that many young people with Down syndrome were aware of Down syndrome, it was hypothesised that participants with Down syndrome would self-identify with others who also have Down syndrome. It was hypothesised that all participants with no disability would 'correctly' self-identify with others with no disability. Moreover, it was hypothesised that participants in older age groups would evidence an increased likelihood to 'correctly' self-identify with others of the

same disability status to themselves. This hypothesis was based on the assumption that increasing age is associated with greater social and self-awareness.

On the basis of the above hypotheses, the following predictions were made for participants' responses on the self-identification task:

- i. Participants with Down syndrome will self-identify with photographs of other children with Down syndrome.
- ii. Participants with no disability of the same chronological age as participants with Down syndrome will self-identify with photographs of other children with no disability.
- iii. Participants with no disability younger than participants with Down syndrome will self-identify with photographs of other children with no disability.
- iv. Older participants with and without Down syndrome will prove more able to correctly self-identify than younger participants.

### **5.3.3 Task materials and procedure**

This was an extension of the sorting task, described in detail in the previous chapter. After the participants had sorted four photographs of children with Down syndrome and four photographs of a child with no disability into two 'posting boxes', they were shown a self-portrait photograph. The participants' self-portrait photograph was taken at the beginning of the session and printed immediately using a portable printer. Self-recognition was checked and then the participant was invited to put the photograph into one of the two posting boxes.

### **5.3.4 Analysis strategy**

Participants were labeled as having self-identified with either the photograph of a child with Down syndrome or a child with no disability. The frequency with which participants in each disability and age group self-identified with each type of photograph was examined. In order to determine if the observed frequencies for each group differed significantly from chance, the binomial test was used.

### 5.3.5 Descriptive analysis

Table 28 below shows the frequency with which participants in each disability and age group self-identified with each type of photograph.

**Table 28: Frequency of self-identifications with Down syndrome and non-disabled photographs, by participants in each disability and age group**

Disability group	Age group	N	DS photograph	ND photograph
DS	8.00-12.12	9	2	7
	13.00-17.12	18	3	15
	Total	27 <sup>a</sup>	5	22
ND	5.00-7.12	14	1	13
	8.00-12.12	27	0	27
	13.00-17.12	26	1	25
	Total	67	2	65

<sup>a</sup> In the Down syndrome group there was one missing participant for this task.

### 5.3.6 Hypothesis testing

#### *Self-identifications of participants with Down syndrome*

It was hypothesised that participants with Down syndrome would be significantly more likely to self-identify with photographs of other children with Down syndrome. The frequencies show that participants with Down syndrome were more likely to self-identify with photographs of other children with no disability. The finding that 22 out of 27 participants chose the non-disabled photograph was highly significant (binomial,  $p = .002$ , 2 tailed). Therefore, the first hypothesis was not supported. Instead, responses were in the opposite directed to that predicted.

#### *Self-identifications of participants with no disability matched on chronological age*

Participants with no disability of the same chronological age were more likely to self-identify with photographs of other children with no disability. There were 53 participants in total in this group and 52 correctly self-identified with the non-disabled photograph. This was also significant (binomial,  $p = .001$ , 2 tailed). Therefore the second prediction was supported.

*Self-identifications of younger participants with no disability*

It was hypothesised that participants with no disability of a younger chronological age would be more likely to self-identify with photographs of other children with no disability. Of the 14 participants in this group, 13 self-identified with the non-disabled photograph (binomial,  $p = .002$ , 2 tailed). Therefore, the third prediction was supported.

*Self-identifications of two age groups of participants with Down syndrome*

It was hypothesised that participants in the older age group would be significantly more likely to correctly self-identify with others with Down syndrome than those in younger age group. The frequencies clearly indicate there was little difference between the self-identifications made by participants according to age group. Therefore, the final prediction was not supported. Instead, participants in all age groups almost exclusively self-identified with the non-disabled photographs.

*Self-identifications of three age groups of participants with no disability*

It was hypothesised that participants in the older age group would be more likely to self-identify with others with no disability than those in younger age group. The frequencies clearly indicate there was little difference between the self-identifications made by participants according to age group. Instead, participants in all three age groups almost exclusively self-identified with the non-disabled photographs. Therefore, the final prediction was not supported.

### **5.3.7 Post hoc analysis**

As in previous tasks, the possibility that participants' self-identifications were related to their verbal age was also explored. A point-biserial correlation indicated this was not the case ( $r_{pb} = .183$ ,  $n = 27$ ,  $p = .362$ , 2 tailed).

### **5.3.8 Discussion**

The results from this task clearly indicate that all participants self-identified with the photograph of a non-disabled child. The self-identification of participants with Down syndrome with non-disabled children has obvious significance. This discussion will be devoted to considering the meaning of this finding.

Firstly, it is important to note that the frequencies present strong evidence that the results are not attributable to any difficulties participants had with the task. Since the overriding majority of participants with Down syndrome identified with the non-disabled children, it is clear that their choices were not haphazard or because they did not understand the task. If that had been the case, one would have expected more participants with Down syndrome to have accidentally 'correctly' self-identified with children with Down syndrome. In addition, it would have been reasonable to expect a relationship between participants' responses and their verbal mental age.

So, if one takes the finding as truly reflecting participants' self-identifications with others, the crux of the issue in interpreting the result is whether participants with Down syndrome were choosing the non-disabled photograph in genuine error about their identity, or if they were motivated to choose to identify with the non-disabled children. To suggest that participants identified with the non-disabled children because they all genuinely thought they belonged with that social group would fit with the findings of the qualitative studies by Todd and Shearn (1997) and Todd (2000). These researchers reported that adults with intellectual disabilities were unaware of their disabled identity because such information was often hidden from them by significant others. Alternatively, it may have been the case that the participants with Down syndrome knew that they 'belonged with' the other children with Down syndrome, but were motivated to identify with the non-disabled children instead. There are two reasons why participants may have been motivated to choose the non-disabled children as being similar to the self. Firstly, it has been argued that children develop a lay theory that 'what is familiar to me is good' (Cameron et al. 2001). The families and communities that children with Down syndrome grow up in tend to be filled with non-disabled individuals, and the people that are more familiar to children with Down syndrome are non-disabled. Hence, the children might have been motivated to self-identify with non-disabled children because they were more familiar and thus preferred.

A second reason why children with Down syndrome may have been motivated to choose to self-identify with the non-disabled children was that they had picked up on social messages about the relative value of members of these groups in society, i.e. the stigma associated with Down syndrome. In other words, children were motivated to identify with the non-disabled children as they perceived them to be more favoured by society. A similar argument was put forward to explain the findings of studies in which black minority

children were found to self-identify with photographs of white children (Spencer and Markstrom-Adams, 1990).

Recently, in the USA, Katz (2003) found that while the accuracy with which Black and White children self-identified with photographs of Black or White children rose in a linear fashion with age until the children were around 30 months old, the accuracy of the Black children then began to decrease while the White children continued to get more accurate. Since Black children's performance had been on par with their white peers up until 30 months it was suggested that cognitive factors were not responsible. Instead, Katz (2002) argued that the Black children had begun to become aware of the differential value attached to these groups by society and were motivated to self-identify with the children they perceived to be more socially favoured (Katz, 2002). In addition, the researchers reported that over half of the Black children did not respond to the question and seemed very uncomfortable. However, it should be borne in mind when interpreting Katz's findings that their measures were forced choice. This means that the children's choice of one photograph cannot be inferred as outright rejection of the other, just that children were sensitive to their relative social value (Cameron, Alvaraz, Ruble and Fuligni, 2001).

Even though the findings from this task were relatively clear cut, the interpretation remains complex. These issues will be returned to in an overall discussion of the findings from the experimental studies.

## **5.4 Adjective Attribution task**

In this chapter, the purpose of the 'adjective attribution task' will be explained, the hypotheses will be outlined and the method described. Then, the results will be described and a short discussion of the findings will be provided.

### **5.4.1 Purpose of task**

The purpose of this task was twofold. Firstly, it was designed to investigate whether participants' views of children with Down syndrome were in line with the social stereotype of the condition. Secondly, the task was intended to explore how participants with Down syndrome viewed themselves in relation to the stereotyped views held about people with Down syndrome.

### 5.4.2 Hypotheses

It was hypothesised that all participants would hold views about children with Down syndrome that reflect the cultural stereotypes of intellectual disability and Down syndrome. This was hypothesised because all children have been socialised into the same society, where these views prevail. Participants' knowledge of the stereotype was assumed to increase with age. Therefore, it was hypothesised that older participants would hold more stereotypical views than younger participants. With regards to participants' self-portrait photograph, it was hypothesised that participants with Down syndrome would hold stereotypical views of themselves. Participants with no disability would be expected to hold more typical views of self, reflecting ordinary views of children and young people.

Based on these hypotheses, the following predictions were made.

- i. Participants with Down syndrome will attribute more stereotypical traits to the photographs of children with Down syndrome than photographs of children with no disability.
- ii. Participants with no disability the same chronological age as participants with Down syndrome will attribute more stereotypical traits to the photographs of children with Down syndrome than children with no disability.
- iii. Participants with no disability younger than participants with Down syndrome will attribute more stereotypical traits to the photographs of children with Down syndrome than to children with no disability.
- iv. Older participants with Down syndrome will attribute more stereotypical traits to the Down syndrome photographs than those in younger age groups.
- v. Participants with Down syndrome will attribute stereotypical traits to their own photograph, as they did the photographs of other children with Down syndrome.
- vi. Participants with no disability of the same chronological age will attribute more typical traits associated with children and young people to their own photograph.
- vii. Participants with no disability younger than participants with Down syndrome will attribute more typical traits associated with children and young people to their own photograph.



### 5.4.3 Task materials and procedure

The task began with participants being introduced to the same two rectangular 'posting' boxes used in previous tasks. A picture illustrating a simple phrase that can be used to describe a person and its polar opposite was attached using Velcro on the front vertical side of each box. The descriptors were chosen to reflect cultural ideas about intellectual disability, the likely lived experiences of young people with intellectual disability and social stereotypes associated with Down syndrome (Wishart and Johnston, 1990). The descriptor illustrations are shown in figures 16 to 22.

There were seven descriptor pairs and each pair of illustrations was presented on two boxes, one at a time. For each pair of illustrations, participants were shown three photographs in succession. These were presented on the table top in front of the two posting boxes. One photograph depicted a child with Down syndrome, another depicted a child with no disability and the final photograph was a self-portrait of the participant. A different pair of matched photographs of children with Down syndrome and no disability was used for each descriptor pair. Thus, there were seven photographs of a child with Down syndrome and seven of a child with no disability used in this task. Participants were shown photographs depicting others of the same gender as themselves. As each photograph was presented, the participant was invited to look at it and then post it into one of the two boxes according to which illustration described the photographed child best. The experimental set up for the Adjective task is shown in figure 23.



Figure 16: Illustrations depicting descriptors 'friendly' and 'not friendly'



Figure 17: Illustrations depicting descriptors 'good' and 'naughty'

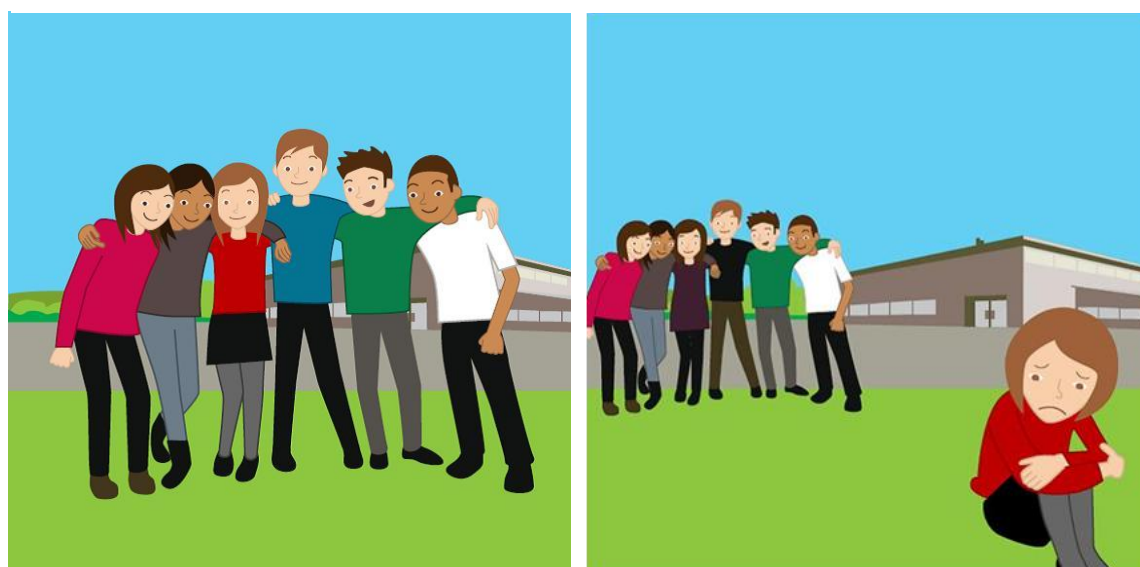


Figure 18: Illustrations depicting descriptors 'has lots of friends' and 'lonely'



Figure 19: Illustrations depicting descriptors 'happy' and 'sad'

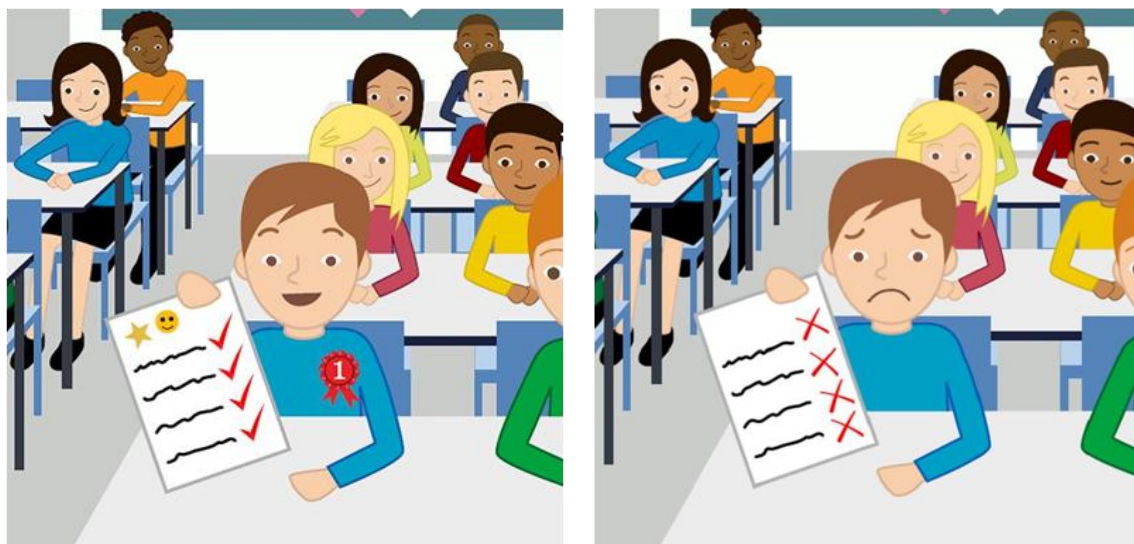


Figure 20: Illustrations depicting 'clever' and 'stupid'

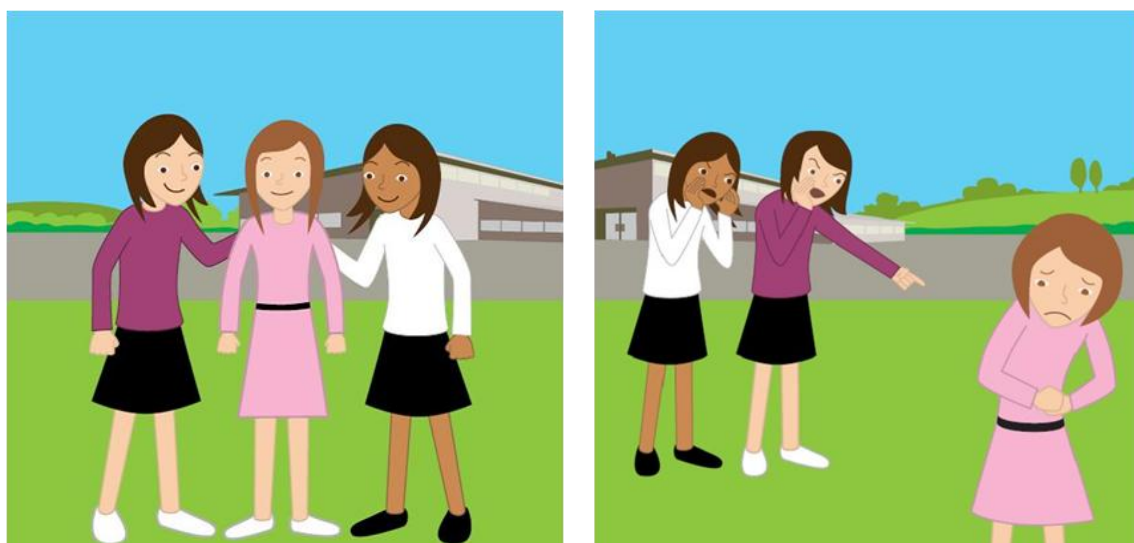


Figure 21: Illustrations depicting descriptors 'people are nice to her' and 'people call her names'



Figure 22: Illustrations depicting descriptors 'can do things on her own' and 'needs help to do things'



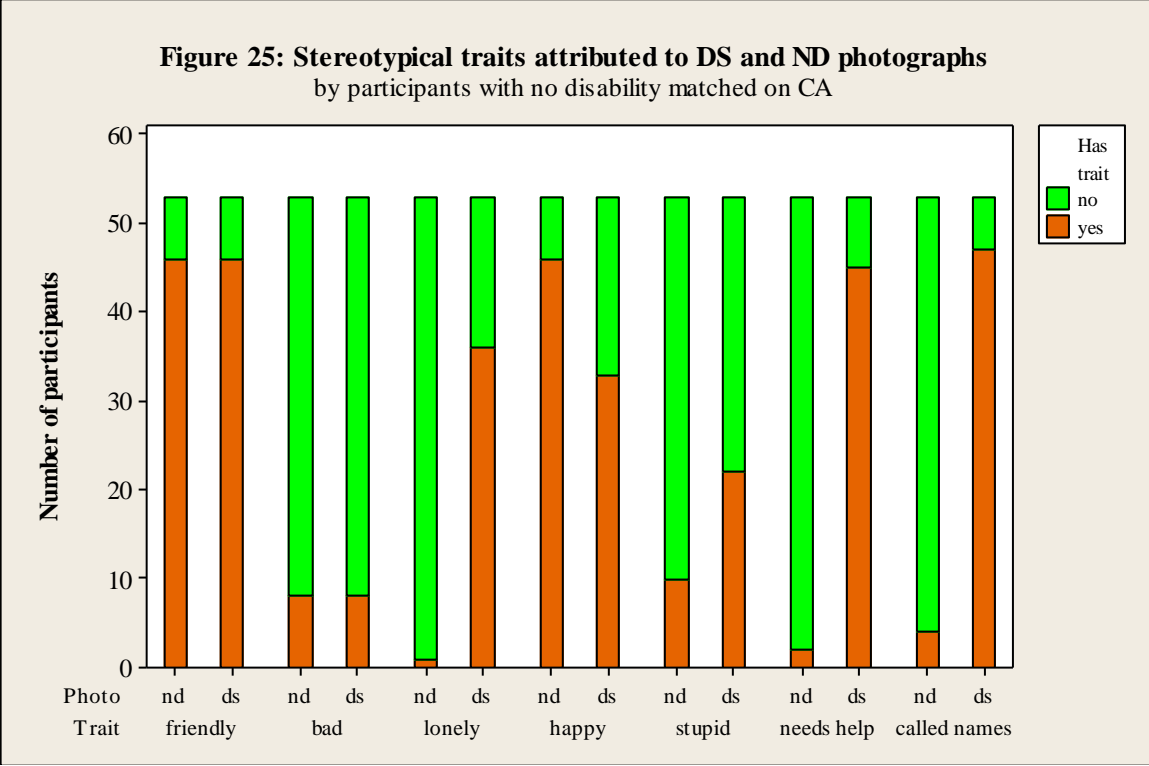
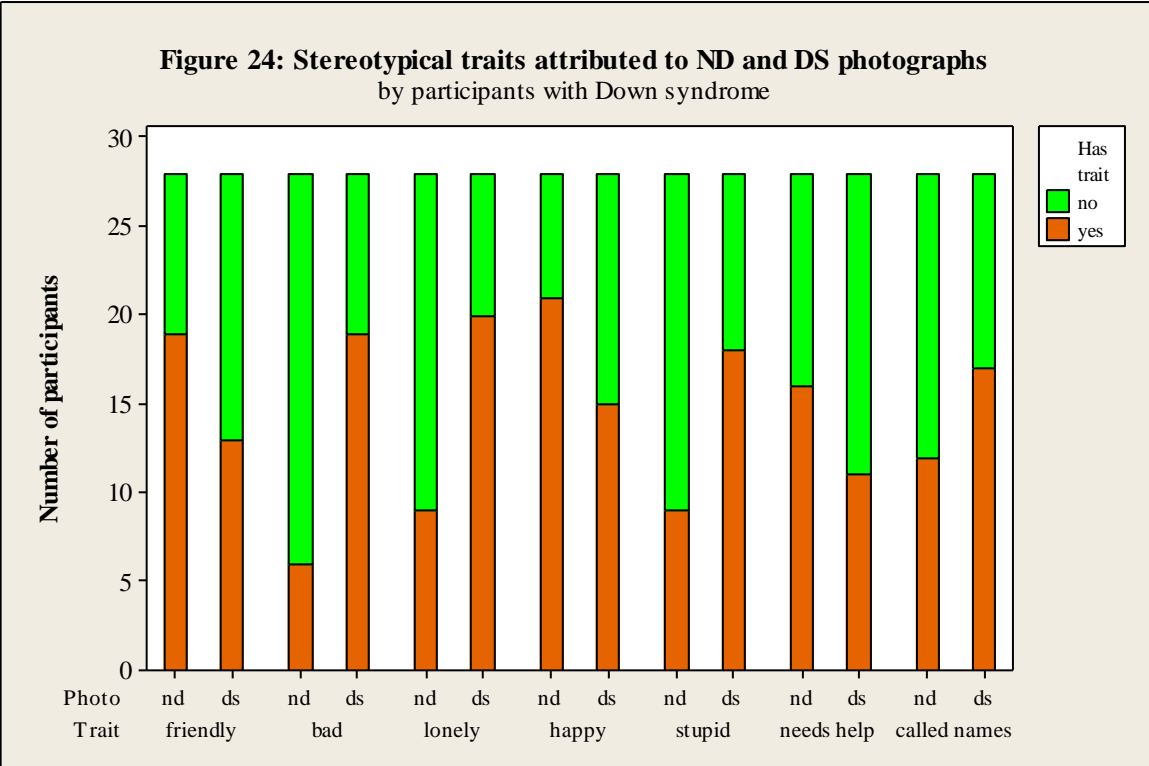
**Figure 23: Experimental set up for the Adjective Attribution task**

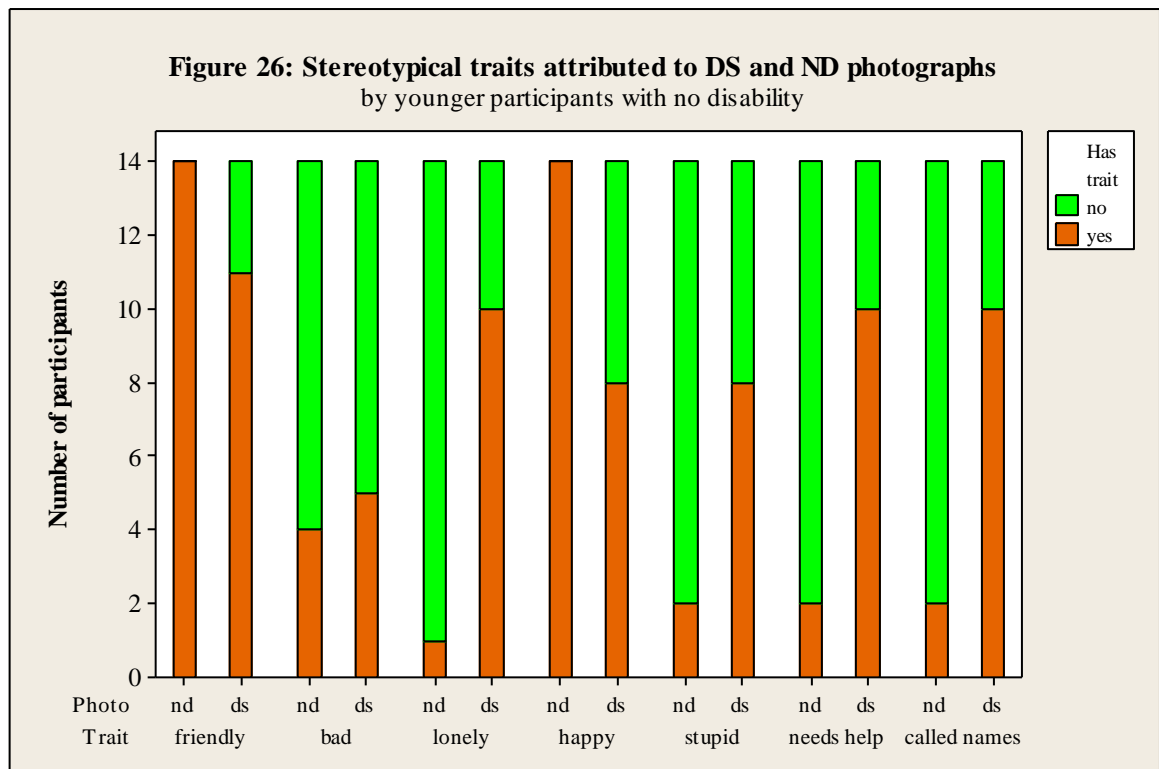
The first section of the analyses will deal with predictions 1-4, analyses relating to participants' self-attributions will be dealt with in the following section.

#### **5.4.4 Analysis strategy (attributions to others)**

There were seven pairs of traits in the task. Each pair comprised a trait that was stereotypical of Down syndrome and its opposite. Participants were asked to choose which trait of each pair applied to a photograph of a child with Down syndrome and a photograph of a non-disabled child. Descriptive analysis centred on examining the frequency with which participants choose each trait option for the Down syndrome and non-disabled photographs. This was done for each participant group separately.

Figures 24 to 26 show the frequency of participants who attributed each stereotypical trait to the photographs of children with Down syndrome and no disability.





The frequency data in figures 24 to 26 indicate that the participants did not respond in terms of a social stereotype but instead according to whether the traits were positive or negative. Thus, participants used the task in a different way from that intended. Rather than judging photographed children on stereotypes, participants based their responses on whether the adjectives were positive or negative. Some stereotypes of Down syndrome could be viewed positively, for example, 'happy' and 'friendly'. Therefore, the focus was shifted to look at whether participants' responses were positive or negative and the hypotheses were adjusted accordingly.

The new predictions are set out below:

- i. Participants with Down syndrome will attribute more positive traits to the photographs of children with no disability compared with photographs of children with Down syndrome.
- ii. Participants with no disability of matched on chronological age will attribute more positive traits to the photographs of children with no disability compared with photographs of children with Down syndrome.

- iii. Participants with no disability who were younger than the participants with Down syndrome will attribute more positive traits to the photographs of children with no disability compared with photographs of children with Down syndrome.
- iv. Participants in older age groups will be less positive about the Down syndrome photographs than those in younger age groups.

In order to test the predictions, it was necessary to compare the mean number of positive traits attributed to the Down syndrome photograph and the non-disabled photograph by participants with and without Down syndrome. Exploratory analyses were first carried out to determine if the photograph positivity scores for each group of participants met the assumptions of normality and homogeneity of variance for parametric analysis.

**Table 29: Tests of normality and homogeneity for photograph positivity scores from participants in each disability and age group**

Photo	Group	Kolmogorov-Smirnov			Levene's test of homogeneity		
		Statistic	df	Sig	Statistic	df	Sig
DS	DS	.186	28	.014	4.720	2, 92	.011
	ND CA	.171	53	.001			
	ND young	.206	14	.109			
TD	DS	.170	28	.037	9.531	2, 92	.001
	ND CA	.320	53	.001			
	ND young	.290	14	.002			

Table 29 shows that the photograph positivity scores from all participant groups violated the assumption of normality and homogeneity of variance (with the exception of the positivity score for the Down syndrome photograph from the non-disabled younger group). Therefore, non-parametric tests were employed.

In order to test the first prediction, a Wilcoxon test was carried out on the number of positive traits participants with Down syndrome attributed to the Down syndrome photograph and the non-disabled photograph. Similarly, a Wilcoxon test was used to assess the prediction that non-disabled participants of the same chronological age will attribute more positive traits to the photographs of children with no disability compared to photographs of children with Down syndrome, and the fourth prediction that participants with no disability who were younger than participants with Down syndrome will attribute

more positive traits to the photographs of children with no disability compared to children with Down syndrome. Potential age group differences were explored using the Mann-Whitney U test on the two age levels of the Down syndrome and non-disabled chronological-age matched group.

### 5.4.5 Descriptive analysis

The bar chart in figure 22 shows the trait attributions made by participants with Down syndrome to photographs of children with Down syndrome (DS) and children with no disability (ND). There were 28 participants with Down syndrome. The bar chart shows the proportion of participants who attributed positive and negative traits to each type of photograph.

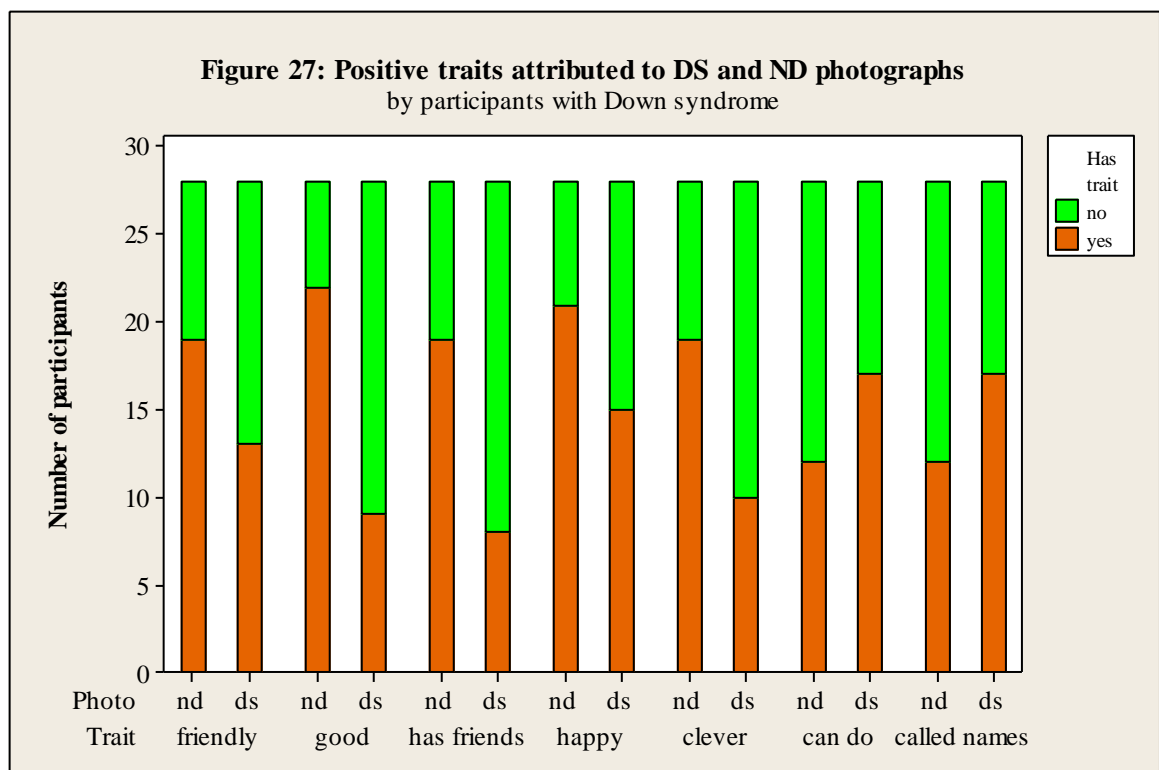


Figure 27 shows that participants with Down syndrome were less likely to think the children with Down syndrome were friendly compared to the non-disabled children. Similarly, they were more likely to think the children with Down syndrome were bad, lonely, unhappy and stupid, than the children with no disability. A slightly higher proportion of participants with Down syndrome thought the children with Down syndrome could do things alone compared with the non-disabled children. Finally, more participants



thought the children with Down syndrome would get called names than their non-disabled peers.

Figure 28 below shows the attributions made by participants in the no disability chronological-age matched group. There were 53 participants in this group. Again, the graph shows the proportion of participants who attributed the positive or negative traits to each photograph type.

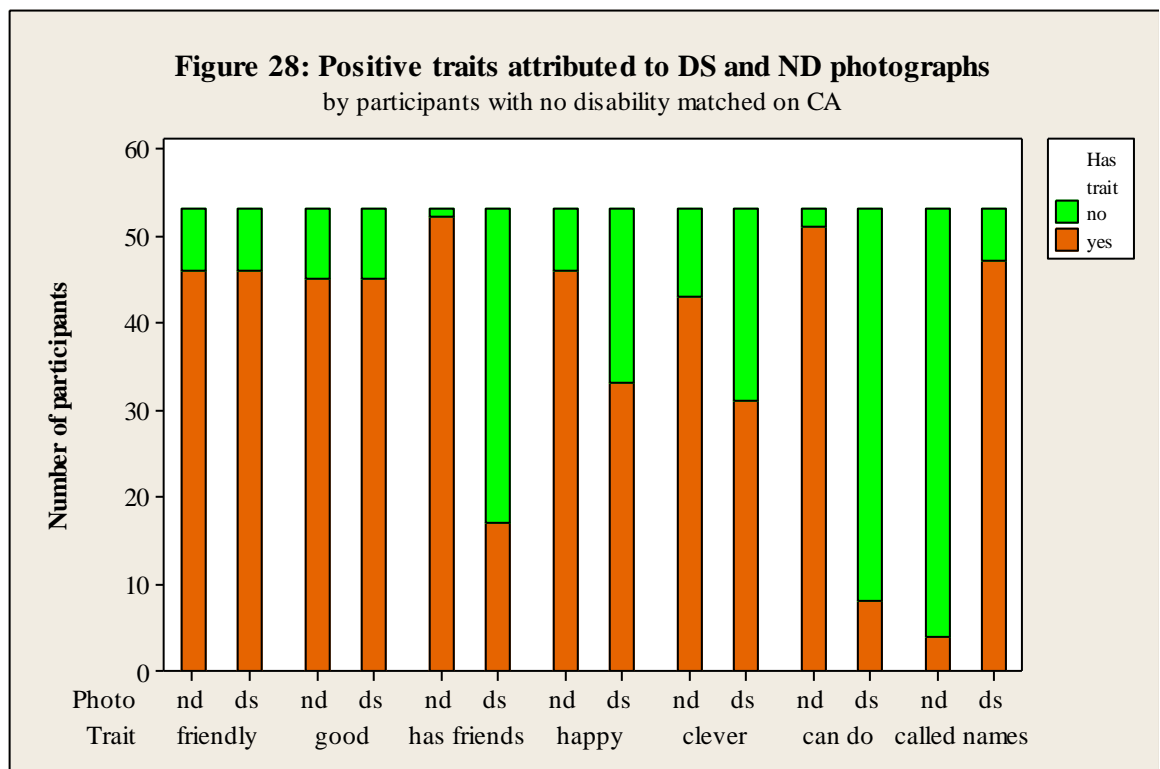
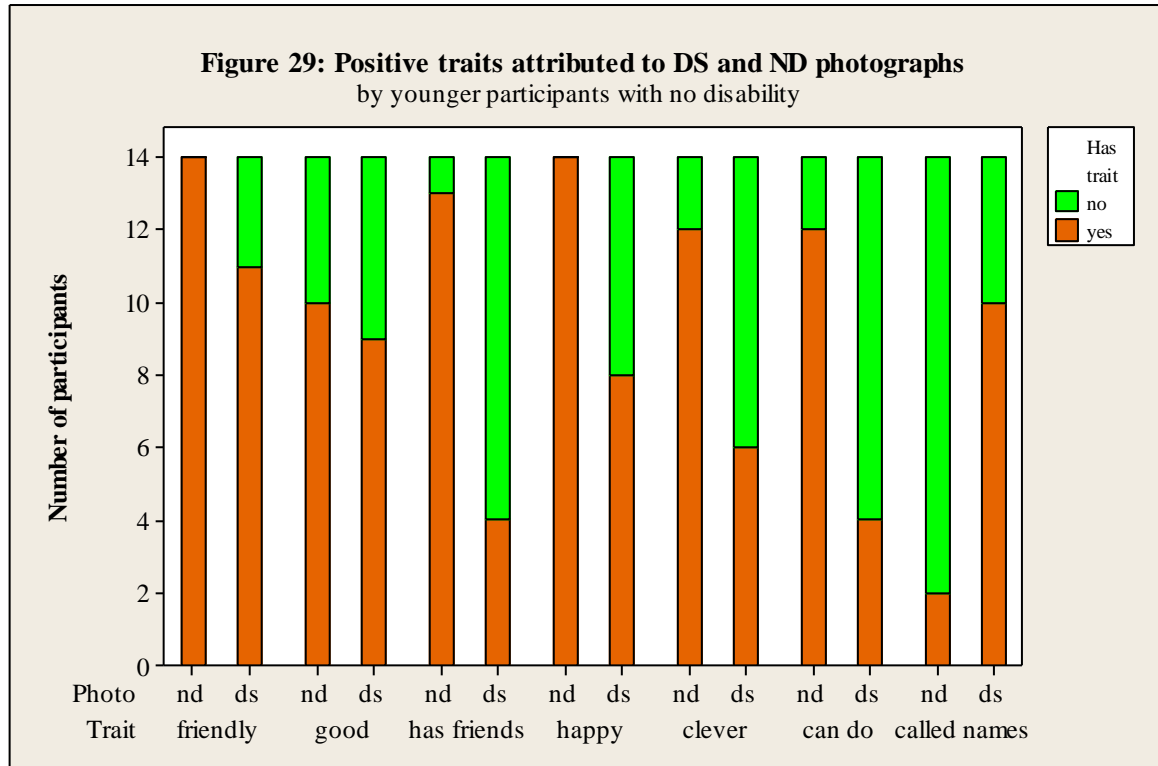


Figure 28 shows that there was less variability in the responses of participants in this group. Most participants thought the children with Down syndrome were just as friendly and good as the non-disabled children. However, they were more likely to think the children with Down syndrome were lonely compared to the non-disabled children. They were also slightly more likely to think the non-disabled children were happy and clever than those with Down syndrome. Finally, participants were more likely to think the children with Down syndrome would need help and get called names.

Figure 29 below shows the attributions made by participants in the no disability younger age group. There were 14 participants in this group.

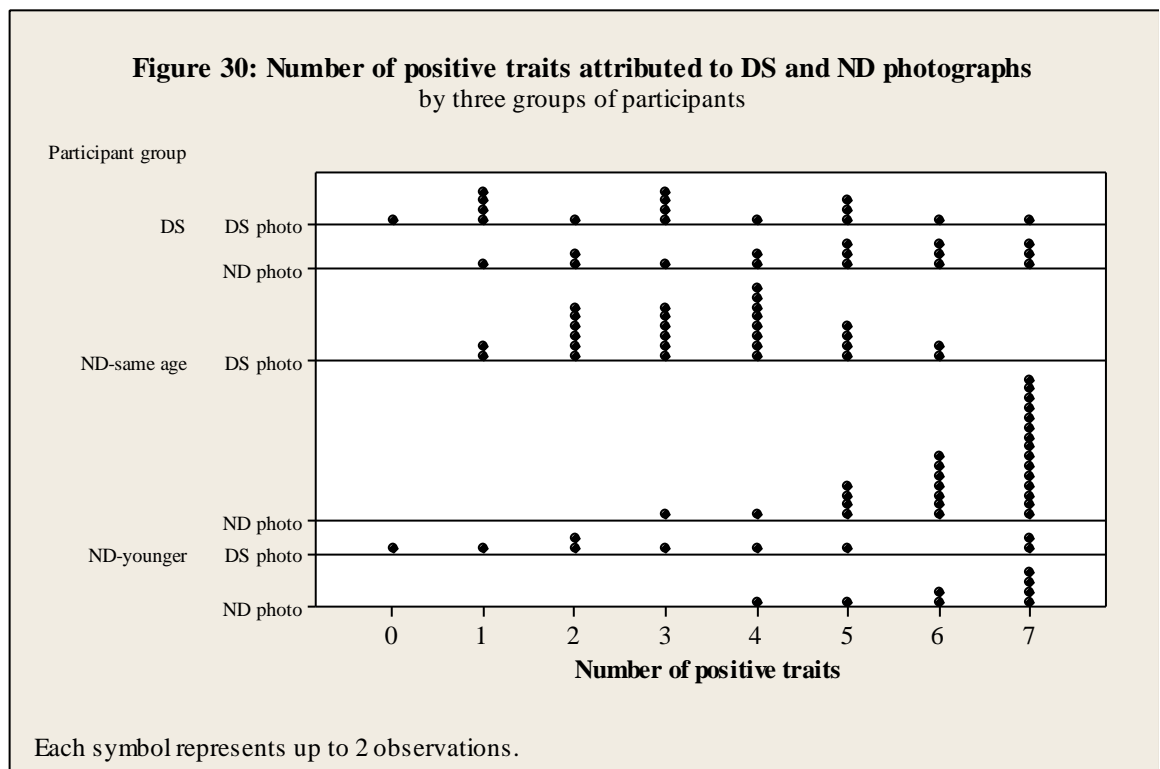


The trait attributions by participants with no disability in the younger age group showed that compared to children with Down syndrome, they were more likely to think the non-disabled children were friendly, would have friends, be happy and clever. Participants in this group thought that children with Down syndrome were just as good as those with no disability. Finally, participants were more likely to think the children with Down syndrome would need help and get called names compared to those with no disability.

Bar charts 27 to 29 show that all participant groups, both with and without Down syndrome, all attributed less positive traits over all to the photographs of children with Down syndrome. However, the pattern of attributions groups made differed. Participants with Down syndrome did show a general negativity about children with Down syndrome, in that they tended to attribute all the negative traits to the Down syndrome photographs and the positive ones to the non-disabled photographs. Participants in the non-disabled groups were slightly more positive about Down syndrome and appeared to be more selective in the negative traits they chose to attribute to them. For example, the traits 'friendly' and 'good' were often attributed to the Down syndrome photographs, while on the

other hand non-disabled participants were likely to attribute the 'needs help' and 'gets called names' traits to the photographs of children with Down syndrome.

The spread of positive scores also differs between the groups. Figure 30 shows this more clearly. There was a broad spread in the number of positive traits attributed to both photograph types by participants with Down syndrome. However, in both groups of participants with no disability a comparable spread was only seen for the photographs of children with Down syndrome and not for the non-disabled photographs. This indicates that there was more agreement among non-disabled participants about what the non-disabled children would be like, than among participants with Down syndrome. Additionally, it suggests that there was less agreement among all participants with regards the attributions of traits to the children with Down syndrome.



#### 5.4.6 Hypothesis testing

The median total number of positive traits that participants attributed to photographs of children with Down syndrome and children with no disability are presented in table 30.

**Table 30: Median (range) number of positive traits attributed to DS and ND photographs**

Disability group	Age group	N	Down syndrome photo	Non-disabled photo
DS	8.00-12.12	10	3 (1-5)	4.5 (1-7)
	13.00-17.12	18	3 (0-7)	5 (2-7)
	Total	28	3 (0-7)	5 (1-7)
ND young	5.00-7.12	14	2.5 (0-7)	6.5 (4-7)
ND ca	8.00-12.12	27	3 (1-6)	7 (4-7)
	13.00-17.12	26	4 (1-6)	6 (3-7)
	Total	53	4 (1-6)	7 (3-7)

*Attributions made by participants with Down syndrome*

It was hypothesised that participants with Down syndrome would attribute more positive traits to the children with no disability than those with Down syndrome. The Wilcoxon test showed that participants in the Down syndrome group were more likely to attribute positive traits to the non-disabled photographs than the Down syndrome photographs ( $T = 56.5$ ,  $p = .001$ ,  $r = -.57$ , 1 tailed). Therefore, this hypothesis was supported.

*Attributions made by participants with no disability matched on chronological age*

It was hypothesised that participants with no disability of the same chronological age would attribute more positive traits to children with no disability than those with Down syndrome. It was found that participants in the non-disabled chronological age matched group were more likely to attribute positive traits to the non-disabled photograph compared to the Down syndrome photographs ( $T = 6$ ,  $p = .001$ ,  $r = -.82$ , 1 tailed). Therefore, this hypothesis was also supported.

*Attributions made by younger participants with no disability*

It was hypothesised that the participants with no disability who were younger than the Down syndrome group would attribute more positive traits to children with no disability than children with Down syndrome. This hypothesis was also supported ( $T = 0$ ,  $p = .001$ ,  $r = -.79$ , 1 tailed).

### *Attributions made by different age groups of participants with and without Down syndrome*

It was predicted that older participants would show an increased likelihood of attributing positive traits to the non-disabled photographs compared with the Down syndrome photographs, than younger participants. The medians in table 31 show that in all three groups of participants there was minimal difference in the number of positive traits attributed to the photographs by participants in younger and older age groups. Therefore, the fourth prediction was not supported.

#### **5.4.7 Post hoc analysis**

To explore possible relationships between verbal mental age and the number of positive traits attributed to the photographs of children with Down syndrome and photographs of non-disabled children, correlational analyses were carried out. These analyses indicated that there was a positive correlation between participants' verbal mental age and the number of positive traits attributed to the non-disabled children, by participants with Down syndrome ( $\tau = .469$ ,  $n = 28$ ,  $p = .001$ , 2 tailed). There was no correlation between verbal mental age and the number of positive attributions made to the Down syndrome photographs for participants with Down syndrome ( $\tau = .047$ ,  $n = 28$ ,  $p = .744$ , 2 tailed). Nor was there a correlation between verbal mental age and number of positive attributions made by participants with no disability to the Down syndrome photographs ( $\tau = .115$ ,  $n = 67$ ,  $p = .205$ , 2 tailed) or the non-disabled photographs ( $\tau = -.002$ ,  $n = 67$ ,  $p = .981$ , 2 tailed).

During the adjective attribution task, participants were asked to attribute traits to their own self-portrait photograph. This chapter will now turn to consider the self-attribution of traits made by participants and how they compare to their attributions to others.

#### **5.4.8 Analysis strategy (attributions to self and other)**

The self-attributions made by participants in each group were compared to the attributions they made to the photographs of children with and without Down syndrome. The key purpose of this comparison was to find out if participants with Down syndrome viewed themselves in a similar fashion to how they viewed the photographs of others with Down syndrome. To re-cap, it was hypothesised that participants with Down syndrome would view themselves in a similar way to others with Down syndrome i.e. negatively compared to others with no disability. Similarly, it was hypothesised that participants with no disability would view themselves in a

similar way to others with no disability, i.e. positively compared to others with Down syndrome. Potential age differences across age groups were also explored. It was hypothesised that participants in older age groups would be more likely to view themselves in line with their views of others of the same disability status.

The following predictions were made based on these hypotheses.

- i. Participants with Down syndrome will be more likely to attribute negative traits to their own photograph, reflecting negative perceptions of Down syndrome.
- ii. Participants with no disability of the same chronological age will be more likely to attribute positive traits to their own photograph.
- iii. Participants with no disability in the younger group will be more likely to attribute positive traits to their own photograph.

The analysis was carried out in the same way as participants' trait attributions above. Firstly, the frequency of participants' individual trait attributions to their self-portrait photograph and the Down syndrome and non-disabled photographs were examined and compared. This was done for each participant group separately. Exploratory analysis showed that the numbers of positive traits participants in each group attributed to their self-portraits violated assumptions of normality and homogeneity of variance (please see table 31 below). The Wilcoxon test was therefore used to test the above predictions statistically.

**Table 31: Tests of normality and homogeneity of variance self-photograph positivity scores of participants in each disability group**

		Kolmogorov-Smirnov			Levene's test of homogeneity		
Self-portrait	DS	.271	27	.001	22.081	2, 91	.001
	ND CA	.483	53	.001			
	ND young	.478	14	.001			

### 5.4.9 Descriptive analysis

Figure 31 shows the attributions made by participants with Down syndrome to their own photograph and photographs of others with Down syndrome and others with no disability.

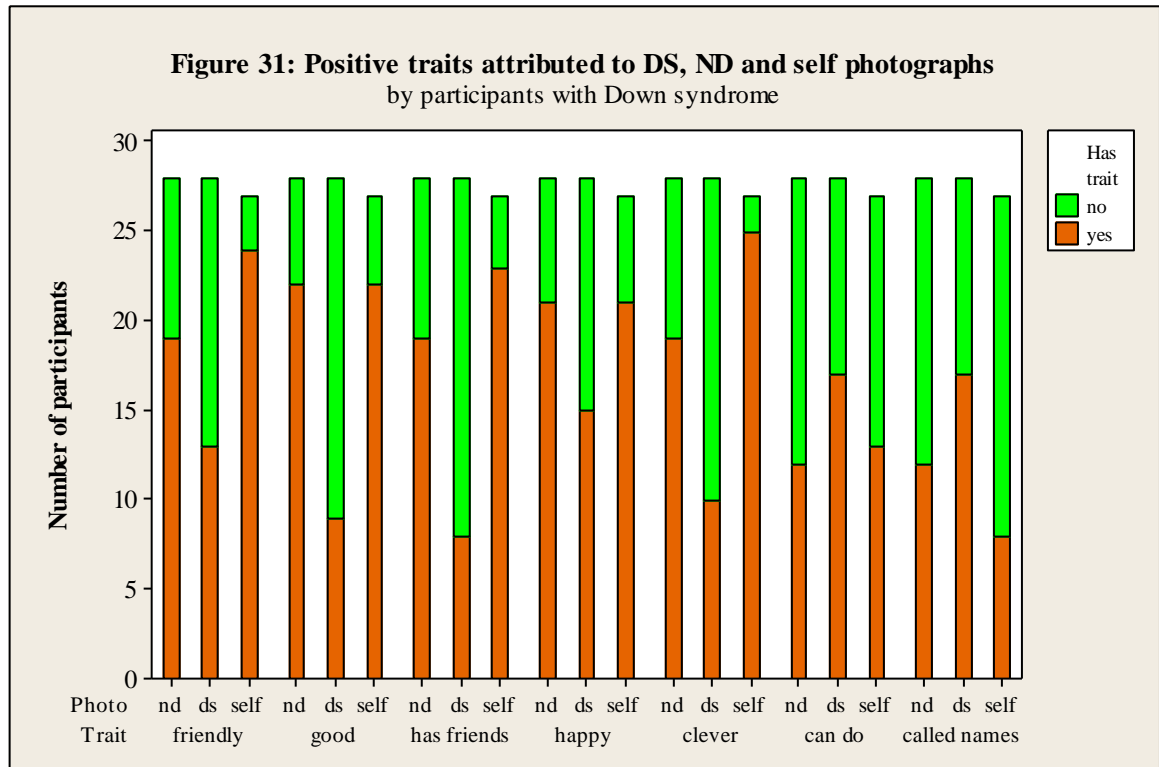


Figure 31 shows that contrary to the prediction that participants with Down syndrome would view themselves in line with others with Down syndrome, their responses indicate that they viewed themselves in a similar way to others with no disability. That is, participants with Down syndrome were, in the main, positive about themselves. For those traits where they were less positive, they were also less positive about the non-disabled photographs. For example, both the non-disabled photographs and self photographs were more often seen as friendly, good and having friends, while roughly half the group thought both the non-disabled and self photographs would need help. Thus, the data suggests the first prediction is not supported.

Figure 32 shows the attributions made by participants in the non-disabled chronological-age matched group.

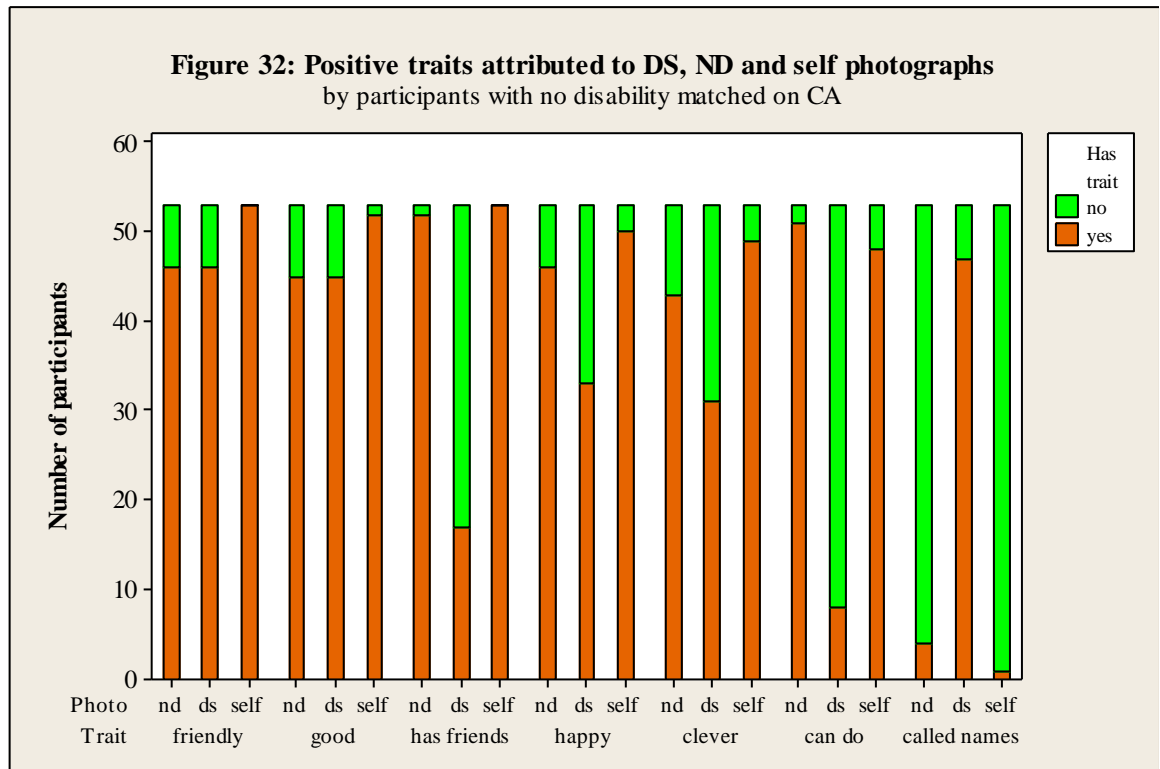
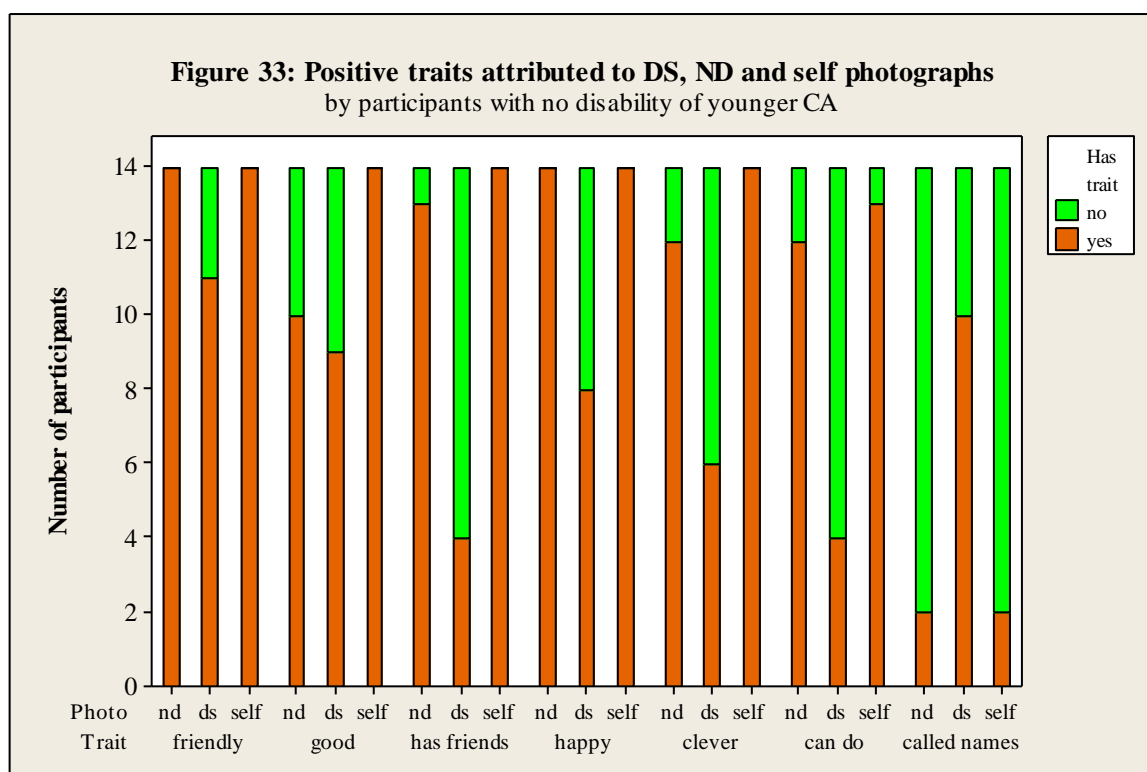


Figure 32 shows that participants in this group were consistently positive about themselves. Further, in the main, participants with no disability of the same chronological age were more positive about themselves than the photograph of a non-disabled other.

Figure 33 shows the attributions made by participants in the younger non-disabled group. Again, the graph shows that participants in this group were consistently positive about themselves. It shows that participants with no disability of younger age were as positive about themselves as the photographs of non-disabled others, if not more. This was in contrast to their views of photographs of others with Down syndrome.





#### 5.4.10 Hypothesis testing

In order to test the predictions, the median number of positive traits participants attributed to their own photograph was compared the number of positive traits they attributed to the photographs of others of the same disability status. The medians are presented in table 32 below. The Wilcoxon test was used to test the predictions statistically.

**Table 32: Median (range) number of positive traits attributed to three types of photograph: children with Down syndrome, children with no disability and participants' own photograph**

Disability group	Age group	N	Down syndrome	Non-disabled	Self
DS	8.00-12.12	10	3 (1-5)	4.5 (1-7)	7 (1-7)
	13.00-17.12	18	3 (0-7)	5 (2-7)	6 (2-7)
	Total	28	3 (0-7)	5 (1-7)	6 (1-7)
ND younger	5.00-7.12	14	2.5 (0-7)	6.5 (4-7)	7 (6-7)
ND CA-matched	8.00-12.12	27	3 (1-6)	7 (4-7)	7 (5-7)
	13.00-17.12	26	4 (1-6)	6 (3-7)	7 (5-7)
	Total	53	4 (1-6)	7 (3-7)	7 (5-7)

#### *Self-attributions of participants with Down syndrome*

It was predicted that participants with Down syndrome would be more likely to attribute negative traits to their own photograph, as they did the photograph of another child with Down syndrome. As indicated by the examination of participants self attributions above,

the Wilcoxon test confirmed that there was a significant difference between the attributions participants with Down syndrome made to their own photograph and those they made to the photographs of others with Down syndrome ( $T = 23.50$ ,  $p = .001$ ,  $r = -.698$ , 2 tailed). This was contrary to the prediction. In light of the frequencies presented above, a Wilcoxon test was then carried out on participants' self-attributions and those they made to the non-disabled photographs. However, this showed that these were also significantly different ( $T = 43.50$ ,  $p = .037$ , 2 tailed,  $r = -.402$ ). The medians suggest that participants were more positive about themselves than the photographs of non-disabled others.

*Self-attributions of participants with no disability matched on chronological age*

It was predicted that participants with no disability of the same chronological age would be more likely to attribute positive traits to their own photograph, as they did the photographs of non-disabled others. The Wilcoxon test showed that the number of positive traits that non-disabled participants in the chronological-age matched group attributed to their self photograph was significantly higher than the number of positive attributions they made towards the photographs of non-disabled others ( $T = -2.950$ ,  $p = .003$ , 2 tailed,  $r = 0.405$ ). The medians indicate that participants were more positive about themselves than the photographs of non-disabled others.

*Self-attributions of younger participants with no disability*

It was predicted that participants with no disability in the younger group would attribute similar levels of positive traits to their own photograph and the photographs of non-disabled others. The Wilcoxon test showed that the number of positive traits that non-disabled participants in the younger group attributed to their own photograph was not significantly different from the number they attributed to the non-disabled other photographs ( $T = -2.11$ ,  $p = .063$ ,  $r = -.564$ , 2 tailed). Therefore, this hypothesis was upheld. However, the test statistic was approaching significance and perhaps it was due to the small sample size that this did not reach significance.

*Self-attributions by participants with and without Down syndrome in different age groups*

It was predicted that older participants would be more likely to attribute traits to their own photograph in a similar way to others of the same disability status than younger participants. However, the minimal differences between age groups rendered this analysis redundant. Younger and older participants were equally positive about themselves.

### 5.4.11 Discussion

Participants with Down syndrome attributed more positive traits to photographs of children with no disability, compared to photographs of children with Down syndrome. Participants in two comparison groups of the same and younger chronological age also attributed more positive traits to photographs of children with no disability compared to photographs of children with Down syndrome. However, the pattern of the attributions made by participants in each disability group differed. Participants with Down syndrome were generally more negative towards photographs of children with Down syndrome compared to photographs of non-disabled children, in that they showed a tendency to attribute the negative trait of every pair to the Down syndrome photographs more than to the non-disabled photographs. Participants with no disability, however, tended to attribute particular negative traits to the photographs of children with Down syndrome. The negative traits participants with no disability selected most often were 'not having many friends', 'needs help' and 'gets called names'.

This finding may reflect a difference of perspective. The attributions made by participants with Down syndrome may have reflected their having picked up on the generally negative social views of Down syndrome and, as a result, they viewed others with Down syndrome in this generally negative light. The negative attributions made by participants with no disability may have stemmed from their observations of children with Down syndrome having particular life experiences, such as needing help in class. What is surprising is that children as young as 5 years old were attributing these traits to children with Down syndrome. Perhaps these traits were salient to young children because they had observed such consequences in their own classrooms.

Non-disabled participants' attributions of the traits 'good/bad' and 'friendly/not friendly' suggest that these were seen as less relevant as descriptions of people with Down syndrome. There also appeared to be differences across age groups with the youngest non-disabled participants being most negative about Down syndrome photographs and the older non-disabled participants more positive and more likely to attribute the 'clever' and 'happy' traits to children with Down syndrome. This age effect might reflect increasing awareness of socially desirable norms as children grow older. In particular, those in the chronological age comparison group made comments during the task that suggested they felt okay about attributing descriptors that referred to negative life experiences of people with Down

syndrome (being called names) or pragmatic realities (needing help). However, negative descriptors such as 'stupid' felt more like judgements of the person and hence were associated with considerable discomfort.

The variability of participants also differed according to group. The spread of the number of positive traits that non-disabled participants attributed to the photographs of others with Down syndrome compared to others with no disability suggests that as a group they were less sure about what people with Down syndrome were like. Participants with Down syndrome showed a similar degree of variability in the number of positive traits they attributed to both the photographs of children with and without Down syndrome.

The analysis of participants' trait attributions to their own photographs revealed that all participants were generally very positive about themselves. Participants in the Down syndrome group viewed themselves more positively than the photographs of others with Down syndrome and the pattern of the attributions indicated that they viewed themselves in a similar way to others with no disability. It was interesting that while participants with Down syndrome said they needed help, they also attributed this trait to the non-disabled photographs more than the Down syndrome photographs. This response warrants further investigation. Participants with no disability in both comparison groups were similarly very positive about themselves, almost exclusively so, and more positive about themselves than the photographs of other children with no disability. Although participants with Down syndrome were positive about themselves, as a group, they were less positive than participants with no disability were about their own photographs.

## **5.5 Discussion of all experimental tasks**

The purpose of this discussion is to bring the results from the experimental tasks together to help interpret perplexing findings. In particular, it was hoped that looking across the findings from the experimental tasks would help to explain the failure of many of the participants to sort the photographs of children with and without Down syndrome.

The findings from the sorting task indicated that participants with Down syndrome did not sort the photographs according to Down syndrome. This was in sharp contrast to non-disabled participants of the same chronological age, who sorted at near ceiling levels. The sorting scores of participants with Down syndrome were more comparable to those of

younger non-disabled participants. Although, the sorting scores of the Down syndrome participants were still lower than the younger non-disabled participants. A positive correlation between verbal mental age and sorting score for the Down syndrome group and the young non-disabled group suggested that verbal mental age could be implicated in responses on the sorting task. It was however unclear whether this relationship was due to awareness of Down syndrome or difficulty with that particular task. In addition, it was noted that some participants with low verbal ages were able to sort the photographs whereas some of those with high verbal mental ages did not. This suggested that verbal mental age alone could not account for the poor sorting performance of participants with Down syndrome.

Results from the preference task indicated that participants with Down syndrome preferred to share activities with the photographed children with no disability, like their non-disabled peers of the same chronological age and those younger in age. Verbal mental age did appear to have some influence, in that higher scores on the BPVS-II were associated with greater preference for photographs of non-disabled children. The opposite trend was found for non-disabled participants, perhaps reflecting their greater awareness of social desirability. However, despite verbal mental age perhaps having some role in the degree of preference shown by participants, the results indicated that all participants stated a preference to share activities with the photographs of children without disabilities.

When asked to categorise themselves, the vast majority of participants with Down syndrome identified with the non-disabled photographs. The finding that only a minority of participants with Down syndrome identified with a photograph of a child with Down syndrome suggested that they were making a clear choice. It remains unclear whether this was a case of mistaken identity or preferred identity.

In the adjective task, participants with Down syndrome were generally more negative about the children with Down syndrome than the children with no disability, as were non-disabled participants in the chronological age matched group and the younger group. However, in examining participants' responses for each trait it became apparent that the pattern of participants' attributions differed according to group. While participants with Down syndrome were more likely to attribute all the negative traits to the Down syndrome photographs in comparison to the non-disabled ones, participants with no disability were more likely to select those traits that reflected observable school and social experiences of

people with Down syndrome. Participants' self-attributions showed that all groups were positive about themselves. However, participants with Down syndrome were slightly less positive than those with no disability. Participants' responses in this task also suggest that they understood the task and trait descriptions, and engaged well with the task.

Looking across the results from the preference task, the self-identification task and the adjective task all suggest that the majority of the participants with Down syndrome were able to discriminate between photographs of children with and without Down syndrome. The results from the sorting task were less readily interpretable on their own. However, in light of the other task results, it seems likely that while verbal mental age may have played some role in level of awareness held by participants, it also cannot be ruled out that at least some participants could have sorted accurately but chose not to. The majority of participants with Down syndrome identified with others with no disability and it was unclear why they did so. In light of the negative views participants indicated they held about Down syndrome in the adjective attribution task, it may be suggested that their self-identification with the non-disabled children was in response to their perceptions of the stigma associated with Down syndrome or more positive societal views of the non-disabled children. Finally, the self-attributions made by participants with Down syndrome suggested that they tended to view themselves positively. Whilst these positive self-perceptions are reassuring, the fact that participants with no disability saw themselves even more positively may indicate some level of self-derogation on the part of those with Down syndrome.

## **5.6 Analyses across tasks**

The three photograph tasks were devised to investigate different aspects participants' awareness of and attitudes towards children with Down syndrome. Therefore, it was envisaged that there would be relationships between the scores on different tasks. This section will explore these potential relationships.

### **5.6.1 Hypotheses**

There are several hypotheses regarding relationships between participants' responses on different tasks. Firstly, it was hypothesised that a greater awareness of Down syndrome will be associated with more negative attitudes towards Down syndrome, due to the

accompanying social stigma. Consequently, it is hypothesised that the ability to categorise others according to Down syndrome will be associated with i) less reported willingness to interact with others with Down syndrome and, ii) more negative views of others with Down syndrome.

Secondly, it was hypothesised that participants with more awareness of Down syndrome would also make more accurate judgements as to whether they have Down syndrome or not.

Thirdly, it was hypothesised that participants' preference to share activities with others with Down syndrome would be associated with how positively they viewed others with Down syndrome.

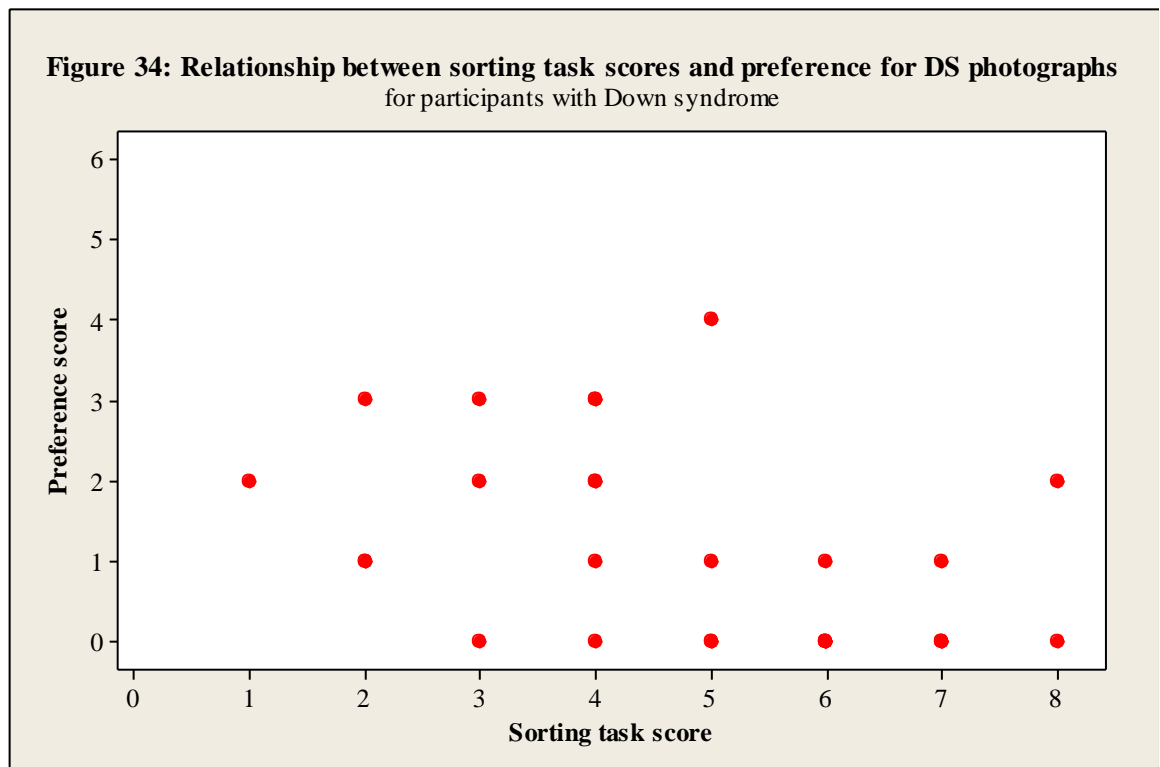
The following predictions were made based on the above hypotheses:

- i. There will be a positive correlation between scores on the sorting task and scores on the preference task. That is those participants who had higher scores for sorting photographs according to whether or not the persons had Down syndrome would indicate a lower preference for interacting with individuals with Down syndrome.
- ii. There will be a significant positive relationship between participants' ability to sort photographs according to Down syndrome and the number of negative traits attributed to the photographs of children with Down syndrome.
- iii. There will be a positive association between scores on the sorting task and the accuracy of participants' self-identification. Specifically, it is predicted that participants who are proficient in sorting photographs according to Down syndrome would also be more likely to accurately self-identify themselves according to this social category.
- iv. There will be a positive correlation between participants' scores concerning their preference for interacting with individuals with Down syndrome and the number of positive traits they attribute to individual with Down syndrome.

## 5.6.2 Hypothesis testing

### *Participants' categorisation of photographs according to Down syndrome and their preference to interact with children with Down syndrome*

Correlation analyses were conducted on participants' preference scores for the Down syndrome photographs and their sorting scores, for each disability group separately. For participants with Down syndrome a significant negative correlation was found between the preference they showed for the Down syndrome photographs and their sorting of photographs according to Down syndrome ( $\tau = -.379$ ,  $n = 28$ ,  $p = .007$ , 1 tailed). This suggests that as participants' ability to differentiate between photographs of young people with and without Down syndrome increased, their stated willingness to engage in activities with individuals with Down syndrome decreased. This relationship is illustrated in figure 34. However no such relationship was found between these variables for participants with no disability of the same chronological age ( $\tau = .042$ ,  $n = 53$ ,  $p > .05$ , 1 tailed) or the younger non-disabled group ( $\tau = -.240$ ,  $n = 13$ ,  $p > .05$ ).



### *Participants' categorisation of photographs according to Down syndrome and their accuracy of self-identification with children with or without Down syndrome*

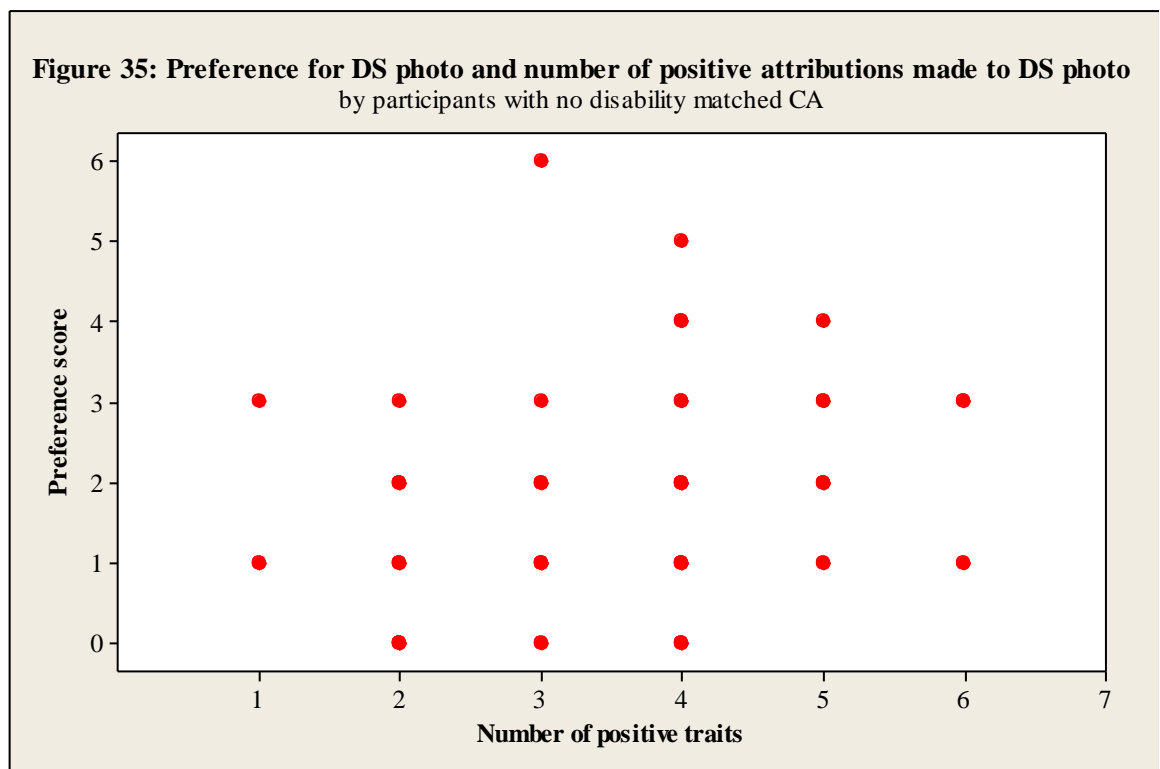
Only five participants with Down syndrome self-identified with the Down syndrome photograph, and one participant in the chronological age matched control group and one of



the younger non-disabled group mistakenly identified with the Down syndrome photograph. Therefore, the lack of variance in the participants' self-identifications made this proposed analysis impossible and unnecessary.

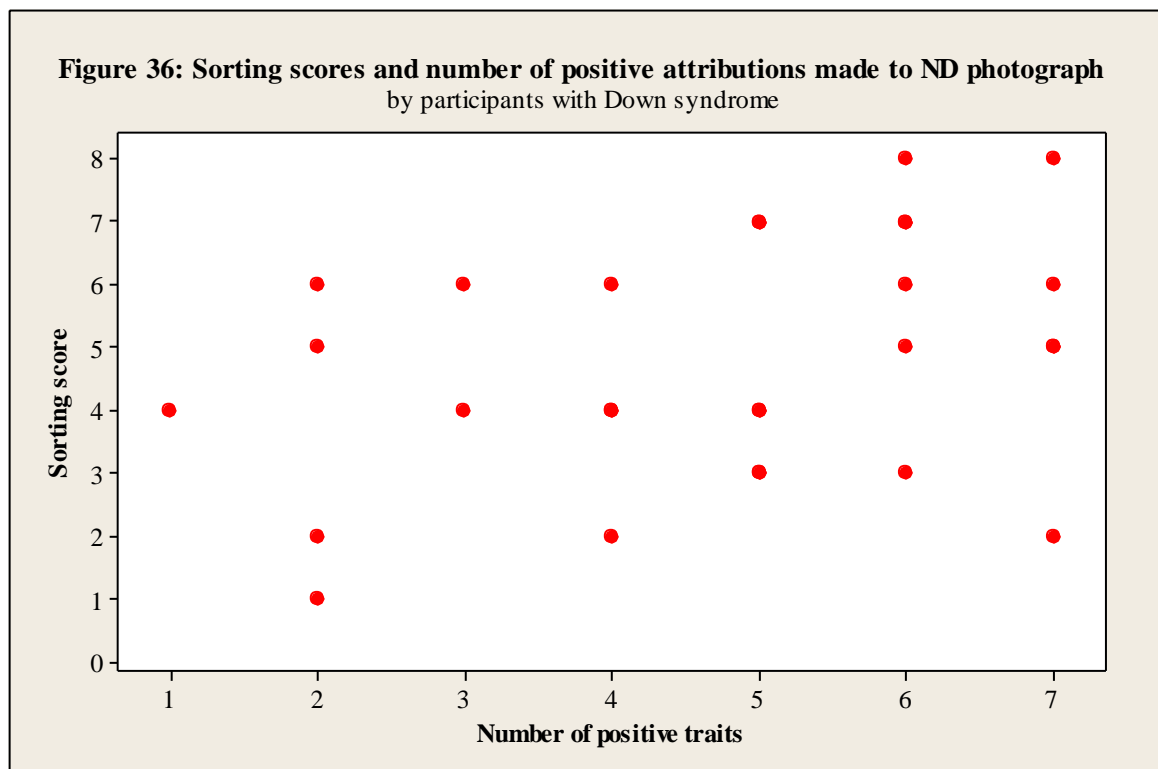
*Participants' willingness to engage in activities with individuals with Down syndrome and the number of positive traits attributed to individuals with Down syndrome*

For the Down syndrome group, there was no relationship between reported willingness to engage in activities with individuals with Down syndrome and the number of positive attributions made about individuals with Down syndrome ( $\tau = .061$ ,  $n = 28$ ,  $p = .350$ , 1 tailed). However, for the non-disabled participants of the same chronological age there was a positive association between their willingness to engage in activities with individuals with Down syndrome and the number of positive traits attributed to those with Down syndrome ( $\tau = .214$ ,  $n = 53$ ,  $p = .028$ , 1 tailed). This relationship is illustrated in figure 35. No association was found for the younger non-disabled group ( $\tau = -.101$ ,  $n = 13$ ,  $p > .05$ , 1 tailed).



*Participants with Down syndrome: Sorting scores and number of positive traits attributed to Down syndrome and non-disabled photographs*

A significant positive correlation was found between the ability to sort photographs according to Down syndrome and number of positive traits attributed to photographs of non-disabled children, for participants with Down syndrome ( $\tau = .258$ ,  $n = 28$ ,  $p = .042$ , 1 tailed). This fits with the assumption that an increased awareness of the social category of Down syndrome would be accompanied by a more favourable view of non-disabled people. This relationship may be found in figure 36. However, no relationship was found between participants sorting score and number of positive traits attributed to those with Down syndrome ( $\tau = .040$ ,  $n = 28$ ,  $p = .394$ , 1 tailed).



*Participants with no disability of the same chronological age: Sorting scores and number of positive traits attributed to Down syndrome and non-disabled photographs*

For those in the non-disabled control group of the same chronological age, a significant positive correlation was found between participants' sorting scores and the number of positive traits attributed to individuals with Down syndrome ( $\tau = .196$ ,  $n = 53$ ,  $p = .046$ , 1 tailed). This is opposite to what would be predicted based on the assumption that a keener knowledge of Down syndrome would be accompanied by a greater awareness of the

stigma associated with it and hence with less positive traits being attributed to the Down syndrome photograph. A significant negative correlation was found between participants sorting scores and number of positive traits attributed to the non-disabled photographs ( $\tau = -.272$ ,  $n = 53$ ,  $p = .013$ , 1 tailed). This is also opposite to what would be predicted based on the assumption that an increased awareness that people may be categorised according to Down syndrome would be associated with increased knowledge of stigma and more positive views of others without Down syndrome. This could be interpreted however as a deliberate attempt to respond in a counter-stigmatised manner from those who were more aware of Down syndrome as a social category.

*Participants with no disability younger in age: Sorting scores and number of positive traits attributed to Down syndrome and non-disabled photographs*

No associations were found in the young non-disabled group between sorting scores and the number of positive traits attributed to the others with and without Down syndrome respectively ( $\tau = -.268$ ,  $n = 14$ ,  $p = .114$ , 1 tailed;  $\tau = -.089$ ,  $n = 14$ ,  $p = .357$ , 1 tailed). However, the small sample size would have reduced the likelihood of finding an association.

### **5.6.3 Discussion**

The analysis resulted in several significant findings, although these were not consistent across disability groups. Relationships between participants' scores across tasks would provide support for the validity of the tasks but small sample sizes and a lack of variance with scores, as participants scored at near ceiling levels on a number of tasks, made it unlikely that consistent associations would be found.

For the Down syndrome group only, there was a correlation between scores on the sorting task and the preference task. This finding suggested that participants with Down syndrome who were more inclined to categorise others according to Down syndrome were less likely to choose to share activities with people with Down syndrome. This association was predicted, as it is in line with the notion that an awareness of the social category Down syndrome and the stigma attached to it, would be linked to more negative attitudes (Beart, Hardy and Buchan, 2005). However, no association between these tasks was found for the non-disabled participants, most likely due to the fact that these participants' sorting and preference scores were at near ceiling levels.

For the non-disabled group matched for chronological age there was an association found between preference task scores and the number of positive traits attributed to the Down syndrome photograph. As the participants' preference for sharing activities with others with Down syndrome increased, so did number of positive traits attributed to the Down syndrome photograph. However, no relationships were found between these variables for the Down syndrome group or the younger non-disabled group.

A relationship was also found between the Down syndrome participants' scores on the sorting task and the number of positive traits attributed to the non-disabled photographs. This indicated that as propensity to categorise others according to Down syndrome increased, positive views of the non-disabled photographs also increased. It makes sense that increased awareness of the social category would be associated with seeing those who do not belong to it more favourably. However, no relationship was found between sorting scores and number of positive traits attributed to the Down syndrome photograph.

For participants with no disability in the chronological age matched group, significant correlations were found indicating that participants who sorted the photographs according to whether the person had Down syndrome or not, attributed more positive traits to the Down syndrome photographs and fewer positive traits to the non-disabled photographs. This pattern was contrary to what was predicted based on an awareness of stigma. However, on reflection, this apparently counter intuitive finding could as easily be interpreted as reflecting an increased social awareness and social conscience, and a deliberate attempt to be positive about people with Down syndrome.

The associations between scores on different tasks offer some support for the validity of the tasks. However, the tasks are not carried out in a vacuum and the context were also revealing about how the participants wished to present themselves to the researcher. In particular, it was evident that the non-disabled participants, at the same chronological age as the Down syndrome participants, did not wish to be viewed as prejudiced or discriminatory. This was in contrast to those with Down syndrome who almost seemed to wish to distance themselves from others with Down syndrome. Thus, the context in which the tasks were carried out appeared to influence the participants' responses it might be wrong to assume that the views expressed by participants on such tasks are necessarily static (Barden et al, 2004).

# Chapter 6:

## Qualitative study: Mothers' Perspective

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### 6.1 Aims

In carrying out this study, the researcher's aim was to explore mothers' experiences and understandings of their child's identity relating to disability and Down syndrome. In particular, the researcher sought to explore mothers' perceptions of their child's developing sense of difference, as a consequence of having a disability.

The researcher began with the following broad research questions: Do mothers believe their child has an awareness of Down syndrome? If so, how do mothers think such awareness came about? How do mothers think their child feels about having Down syndrome? Do mothers think their child's awareness or feelings about Down syndrome have changed over time?

### 6.2 Method

The qualitative method chosen for the study was Interpretative Phenomenological Analysis (IPA). IPA was deemed to be an appropriate method for the study for several reasons. Firstly, the aim of the research was to explore mothers' views of their child's awareness of Down syndrome within the context of their family lives and the wider community, and the IPA method is concerned with the meaning individuals attach to events within social contexts (Smith, 2004). However, in IPA it is also recognised that the researcher plays an integral role in interpreting the data. Secondly, the topic of the present interviews was envisaged to be potentially upsetting, and IPA has been found to be an efficacious approach by researchers exploring other potentially upsetting issues, such as, psychological distress, life transitions and identity (Smith and Osborne, 2008). IPA has also been used successfully in previous research concerning highly sensitive subjects with the parents of people with intellectual disabilities (Reilly, Huws, Hastings and Vaughan, 2008). Thirdly, IPA allows for a highly descriptive and in-depth account of participants' experiences. Therefore, it is a good approach to explore under researched areas.

IPA studies typically involve a sample of 6 to 12 individuals (Smith, 2004). This size of sample is advised because it enables a detailed interpretive account of each case, whilst

also allowing for an analysis of the similarities and differences across cases (Smith and Osborn, 2008).

### 6.2.1 Participants

Nine mothers aged 39-48 years old participated in the study. All were biological mothers to their child with Down syndrome. Five were mothers of a daughter with Down syndrome and four had a son with Down syndrome. The participants' children were aged 9 to 16 years old. All of the children had at least one typically developing sibling. Table 33 shows information about the mothers, their children and the schooling history of their child with Down syndrome. All but one mother lived with their marital partner. Pseudonyms for the mothers and their children are used throughout, to maintain participants' anonymity.

**Table 33: Mother and child information**

Mother (age)	Child (age)	Siblings (age)	Primary Ed	Secondary Ed
Caroline (41)	Henry (15)	Mary (15)	Mainstream	Special
Gail (46)	Daniel (16)	Nick (18)	Mainstream	Special
Sheila (40)	Sophie (14)	Tania (16) Luke (12)	Special	Special
Tessa (48)	Abbie (9)	Mark (12)	Mainstream	n/a
Sarah (42)	Peter (12)	Eoin (16) Arnie (15)	Mainstream	Base in mainstream
Tracy (46)	Harry (10)	Roslyn (15)	Mainstream	n/a
Anne (39)	Lydia (10)	Nathan (7)	Mainstream	n/a
Lorraine (40)	Fiona (13)	Boris (2) Peggy (12)	Mainstream to P6	Special
Michelle (42)	Lucy (15)	Kate (19)	Mainstream	Special

### 6.2.2 Recruitment

Participants were nine mothers of the children who participated in the experimental study. Families of children with Down syndrome were contacted through schools in the West of Scotland and the organisation Down syndrome Scotland. The study information packs were distributed by schools and included an invitation for mothers to take part in the interview phase of the study. Down syndrome Scotland posted an invitation for the study on their website. One mother contacted the researcher directly having seen the advert on the Down syndrome Scotland webpage and the remaining mothers returned the consent form they had received from their child's school.

### 6.2.3 Semi-structured interview

Non-directive, semi-structured interviews were used to gain insight into mothers' views of their child's sense of difference and how they think this emerged over time. The interview topic guide was designed so the interview elicited mothers' views of their child's developing awareness of difference within the context of their child's relationships with others, both within and out with the family. A topic guide was used to help structure the dialogue, however, the researcher also remained sensitive to the topics or concerns that were brought up by the participants themselves and explored these as they arose. The researcher took care before the interview began to inform the participants that she was primarily interested in learning about what they thought as experts on their family.

The topic guide was developed alongside a Clinical Psychologist who has considerable experience of carrying out qualitative research in the field of intellectual disabilities. Much thought was put into how best to put mothers at ease and encourage a dialogue about such a sensitive and emotive issue. The interview began with general questions about family composition and family life. Mothers were then encouraged to talk about their experiences with their child with Down syndrome when they were born and in their early years. The researcher ensured that sufficient rapport had been developed with the participant before asking about their child's relationships with others. The interview addressed the child's relationships with siblings and school peers, and how these may have changed with time. Mothers were also encouraged to describe if and how Down syndrome and/or disability had been spoken about as a family or discussed directly with their child with Down syndrome. If the subject had been discussed, mothers were asked about their child's understanding and feelings about Down syndrome. Mothers were asked about the families' experiences of public attitudes about Down syndrome and any instances of stigma they may have experienced. In addition, mothers were asked if they thought their child was aware of such attitudes. The final section encouraged mothers to talk about their hopes for their child's future and they were asked if there was anything else they would like to discuss. The interview ended with some light discussion of the child's hobbies and interests.

When it was felt necessary and appropriate, the interviewer summarised the key points made by participants to check their understanding. In doing so, the interviewer ensured participants were given the opportunity to correct any misunderstandings. The interviewer

also remained alert to the risk of asking leading questions and tried to avoid doing so. The topic guide was initially piloted with one mother and may be found in Appendix E.

The interviews lasted between 45 minutes and 90 minutes.

### **6.2.4 Procedure**

All participants chose to be interviewed at their home and gave permission for the interview to be recorded using a digital voice recorder. Participants were given the opportunity to ask any questions they had before the interview started and the recorder switched on. They were also informed that they could withdraw from the study at any time, without giving a reason and that if they did choose to withdraw from the study any information they had provided would be destroyed. Demographic information was collected at the end of the interview, when the recorder had been switched off.

### **6.2.5 Researcher reflexivity**

In using IPA, the aim was to explore mothers' views of their child's perceptions and to gain insight into their perspective as far as possible. However, it was also recognised that a researcher can only gain access to the participants' world indirectly through their interpretation of the mothers' reports. In other words, it was accepted that the researchers' interpretation of the interview data will be coloured by her existing beliefs and understanding of the phenomena under study. Similarly, as the interview is a two-way process, the dialogue itself may be influenced by the researcher's views (Smith, 2007). In order to be explicit about the ways in which the interviews may have been influenced by the conceptions of the researcher, personal reflection was undertaken.

For six of the participants, the researcher had seen the participants' child before the interview took place. This helped the interviewer connect with these mothers, since both parties knew the researcher had an idea what their child was like as a person. In the other three cases, the researcher saw the child just after the interview had taken place.

Prior to carrying out the interviews the researcher had read the existing literature on people with intellectual disabilities' awareness of stigma and disability. Such reading had led the researcher to form opinions about the topic and expectations regarding mothers' responses. Existing research suggested that families were not keen to talk about disability to their offspring with intellectual disabilities, because they were acutely fearful of the upset it would cause them. As a result, it was often found that families and support staff alike



tended to believe that people with intellectual disabilities were unaware of public attitudes towards people with intellectual disability and did not feel any sense of difference from others.

Before carrying out the interviews the researcher was quite apprehensive. She had never carried out qualitative research before and was concerned with how well she could encourage and maintain a comfortable dialogue with participants. The researcher was also concerned about upsetting people by asking sensitive questions and imposing on people. In order to carry out the interviews the researcher was forced to override her instinct to not ask sensitive questions that may upset interviewees. The reading the researcher had undertaken added to this anxiety by suggesting that this subject was a taboo subject for families.

During the interviews it became clear that mothers felt strongly about the topic of their child's identity and that, as expected, it was an emotional subject for them. However, what also became clear was that mothers were very keen to talk about it. Mothers seemed to embrace the opportunity to discuss the subject at length. Therefore a significant general finding of this research was that mothers wanted to talk about these issues, perhaps in part because there had been a dearth of opportunity to do so otherwise.

A further challenge experienced by the researcher was that she often found it tempting to offer positive words of support and found it difficult to maintain the distance required in an interview context. However, every effort was made to do so and if the researcher felt that the family would benefit from extra professional support, details of appropriate contacts were provided.

### **6.2.6 Ethical approval**

Ethical permission for the study was obtained from the University of Glasgow Medical Faculty Ethics Committee (Project reference number: FM03510). This is shown in Appendix A.

### **6.2.7 Data analysis**

Interviews were transcribed verbatim by the researcher. Each participant was given a pseudo name and any other potentially identifying information was omitted to ensure

participants' anonymity. The data analysis followed the steps described by Smith and Osborn (2008).

The process began with reading each transcript closely several times, in order to gain familiarity with the content. The researcher then read through the transcript again, this time noting points of interest and significance in the margin. The transcript was re-read and emerging themes were noted. A set of emergent themes and relevant quotes from the transcript was compiled, and connected themes were grouped and organised under overarching theme headings. This process was repeated for each transcript. The resulting overarching themes for all the interview transcripts were then compared and integrated. Finally, a table of all the emergent themes was compiled. The table was used to present the structure of the themes identified and provided the basis for writing up the results.

In order to ensure that the interpretation process was carried out rigorously and was explicit a number of steps were taken. The researcher kept a reflective journal to chart the process of drawing out themes and integrating themes across the transcripts. The researcher also wrote a summary of each interview to help consolidate the themes obtained and ensure they reflected complexity and detail of the narrative as a whole. The researcher also recorded her reflections of each interview after it had taken place, so that the emotional reactions of the interviewees could be used to inform the interpretation of the transcripts. The emerging themes were discussed with a researcher with experience in carrying out IPA analyses. This enabled an audit of the analysis process. Finally, care was taken to return to the original transcript at several points to check the themes were grounded in examples from the interviews (Reid, Flowers and Larkin, 2005).

## **6.3 Results**

The qualitative results will be presented in two parts. The first section will outline the findings concerning the mothers' views of their children with Down syndrome's social relationships. This will provide a context for the second section concerning the mothers' views about their children's awareness of Down syndrome.

### **6.3.1 Section 1: Peer and Social Relationships**

Mothers were encouraged to talk about their child's relationships with school peers. The context of school and relationships with peers was considered to be a setting where a child's sense of difference may emerge and where incidents that highlight difference may

take place. Mothers talked at length about their child's relationships with school peers and it was clear that their child's social life was an area of deep concern for them. At the time of the interview three of the mothers' children were in a mainstream primary school, and the remaining six children were attending a special secondary school. Of the six children who were in secondary school, all but one had attended a mainstream school for most of their primary education.

This section will present themes that emerged in relation to children's relationships with school peers. It will be organised around three major headings. The structure of this section of the results is presented in table 34 below.

**Table 34: Themes around children's relationships with school peers**

1. Mother's concerns about child's relationships with mainstream peers	2. Child's obliviousness to social problems	3. Mum managing the gap
Peer protectiveness	Disinterest in socialising	Providing social opportunities
Growing gap between child and peers	Seeking a different sort of interaction	
Change of heart about special schooling	Satisfied with siblings' friends	
Losing touch	Contrasting account: a growing awareness of difference	

### **1. Mothers' concerns about child's relationships with mainstream school peers**

Mothers expressed many concerns about the quality of their child's relationships with mainstream school peers. This theme had several dimensions and these are discussed below.

#### ***Protectiveness of peers***

Mothers talked about how their child's peers often took on a domineering and caring role towards their child. While this was mentioned by the majority of mothers, the most detailed accounts were given by the mothers of girls. For example, Abbie's mother said:

*She had, a couple of friends who were both em, who don't have Down syndrome, um, one of whom...it was kind of like a maternal relationship, she kind of liked mothering her, ... (Abbie's mum)*

Lydia's mother spoke of how she favoured a friend because she encouraged her daughter and showed her daughter how to do things rather than 'taking over' in a smothering fashion.

*...she was good with her but she didn't 'mummy' her, she would, they were trying to get off the stool one day and she was said to Lydia "right Lydia I'll show you how to get off it" and she encouraged her, but in a nice way, not over thingy way, she was an awful nice wee girl...(Lydia's mum)*

A different perspective was expressed by Peter's mum. She had noticed peers taking on an increasingly protective role towards her son as he grew older. However, she took a positive stance towards this change, choosing to take reassurance from it of her son's wellbeing at school.

*...but once it got to a certain kinda older years of primary, that were when certain kids really noticing that Peter was different in bigger ways, then, but at the same time there wasnae a kid at that school that wouldnae have stood up for him or you know,...(Peter's mum)*

During the interview Peter's mum often referred to the desirability of her son being known by the local community and of nurturing this by having him attend the local mainstream school. This seemed to be a strategy to try to ensure there were as many local people 'looking out for him' as possible and thereby helping to ensure his future safety when he was out and about alone.

In summary, the mothers tended to think that their child's non-disabled peers adopted a protective role towards them. Irrespective of whether the mothers had misgivings about the nature of their child's peer relationships, they realised that these relationships were different from those their child's non-disabled peers enjoyed with each other.

### ***A growing gap from non-disabled peers***

Mothers talked about a gap between their child and mainstream peers that grew wider with age. While this theme was found in accounts from all mothers, it was especially poignant in the accounts of three mothers whose child was in their late primary school years and aged 9-10 years old. For example, Harry's mum said:

*I mean, you know, well the gap gets wider as they older sorta thing, and, even you can see now, the kids that he played with more eh they're growing apart a bit more as they develop more and more, and, well he is developing as well, but yeah, the gap does just widen, you know, when they're younger it's an awful lot easier, in fact I've found that he's just made friends with a younger child at school, who's only in primary three or four, so he sorta plays with younger children now,...(Harry's mum)*

Abbie's mum raised her concern about this gap in relation to gender, as she reflected on the social interactions typical of girls, and the mismatch between their interactional style and her daughter's level of understanding.

*...whereas little girls are all about, particularly, little girls at eight/nine, it's all about, you're my best-est friend, your my second best friend and your third best friend and you're not my friend anymore at all, [laughing] and you know, it's just unbelievably complex, their social hierarchy and their network, and um, that's what I mean about when I say, I mean, see Abbie can't keep up with all that sort of stuff, she'd have no idea what all that sort of stuff means, how, she just finds it all baffling... (Abbie's mum)*

The gap was also expressed in terms of their child not having the same kinds of relationships with peers that they had with one another. There was a sense that mothers wanted for their children the same kinds of friendships that non-disabled peers had with one another, but that the friendships their children had were not the same.

*...And you already see that, although the other kids are perfectly nice to her, she doesn't have the kind of friendships with them that they have, you know, with other kids. (Abbie's mum)*

For Abbie's mother, her daughter's relationships with non-disabled peers were also associated with an uneasiness that related to an inequality inherent in them. This disquiet was perhaps in part linked to an awareness of her child's vulnerability in such a partnership. Further, there was the suggestion that the inequality of her child's relationships with non-disabled peers undermined the authenticity of these friendships. She said:

*...but she does have friends, but it's a difficult one to manage those friendships because you're aware, and I'm always aware that it's not a friendship of equals, and you know (Abbie's mum)*

### ***Change of heart about special school***

Mothers' perceptions of their child's social difficulties at mainstream primary often led to a change of heart regarding secondary education. On the whole, mothers viewed their child's attendance at a mainstream primary school as having been the right decision and a positive experience. However, observing their child's increasing social marginalisation had brought into focus their child's future needs and had led to a change of heart regarding secondary education. While, mainstream schooling continued to be held in high esteem as an ideal, special secondary schools seemed to hold more promise of social opportunity.

*...I think, my gut feeling, is that we'll probably, she'll probably go to special school, because of, because I think, if you can't have good friendships and you can't have meaningful social relationships, then I think you're too isolated and I think it is, I don't think secondary's are very well set up for, to really create those kind of, and at the end of the day, adolescents, you can't create their friendships anyway. (Abbie's mum)*

For Abbie's mum there was a particular sense of sadness and hopelessness when she spoke of the lack of common ground for her daughter to build authentic relationships with typically developing peers at mainstream, as she goes on to say:

*...and thirteen year olds, you know, aren't going to want to come round here and... do what Abbie's doing, you know, voluntarily, you know, or if they did, they'd be very unusual, I think. And the ability, the things they will talk about, you know, they're twelve, they're girls, they'll be talking about boys and fashion, and all the things they talk about and people that they like, and Abbie will still be talking about...well on a good day, she'll be talking about Tracy Beaker, which is the most advanced thing that she does, but it might equally be Balamorie or you know something else...so, it's not going to form, there's no space there, I don't think, for a meaningful relationship...(Abbie's mum)*

Fiona was 13 years old and was currently attending a special secondary school after having been at a mainstream school. Her mother described the situation that led to the decision to support her to leave her mainstream school early and how the isolation experienced by Fiona was particularly blatant when she compared her social circle with that of her typically developing sister who was very close in age. Fiona's mother also described the improvement in her daughter's social life with the move to a special school.

*I would see them in the playground in the morning and I'd think they're all sorta gossiping, you know what girls are like, you know, chatting about each other or what they watched on*

*TV or pop stars and stuff like this, and just sort of the general chat, and I think that a lot of the kind of things sort of went over Fiona's head probably, and you would see sort of wee groups of girls in the morning and then she would be standing in the play ground on her own sometimes, she had a couple of friends who would kind of pull her over and things, but most of the time she would kind of stand herself, whereas Peggy would go and there'd be wee crowds and...(Fiona's mum)*

*There's no way she'd have coped with a big, cos both the high schools in [Scottish town] are quite big eh, ... and socially I think she would have just been completely left out, ...whereas now, they have like, she goes to parties and things with friends and things, so it's nicer. (Fiona's mum)*

Abbie's mum suggested that special secondary schools not only offered more promising social opportunities but also the opportunity for her daughter to compare herself favourably to classmates academically as well. The quote below suggests that for Abbie's mother the opportunity for her daughter to 'shine' in terms of academic ability in comparison to classmates was another important factor in her self-esteem, alongside successful social relationships.

*... and also...she'll never be, if she goes to special school, she'll get an opportunity to shine and I think that's actually quite important as well. (Abbie's mum)*

Despite the positives that ultimately swayed the decision, mothers were conscious of a downside to sending their child to a special school. The special schools in the area tended to be a greater distance away from their home and it was feared the geography would lead to a loss of connection with the local community. In addition, going to special school would mean that school friends would more likely live further away from their child, making socialising outside school hours more difficult.

*...probably special school, and that will be a loss in certain respects, just because of the localness of it, she'll become a bit of an outsider, you know, people will know her, but she'll be the girl with Downs who's at the local shop of whatever but on the upside she'll have hopefully friendships and people that she hangs out with, yeah... (Abbie's mum)*

### **Losing touch**

The gap that mothers saw growing between their child and mainstream peers was often described as ultimately resulting in losing touch with non-disabled friends entirely. Two

mothers talked about a primary school friend who had in the past been a regular companion but whose friendship had been lost due to moving schools or in the transition to secondary school. For example, at the time of interview Daniel was 16 years old. He had attended a mainstream primary school and was currently attending a special education secondary school. His mother said:

*And from every year they will come and then because we are local many of them would come and especially one, he would go to his home, he would come and he would take him to go out with us, and the mum would take Daniel also with them. Unfortunately then they went to secondary schools in different ways and we haven't seen him for a long time.  
(Daniel's mum)*

Lydia's mother spoke about the futility of trying to maintain a friendship after it had begun to break down.

*...she was an awful nice wee girl, and they still keep in touch but she's kind of went away in a different circle and I've, you have to try and keep contact but it's not really, it's not really happened (Lydia's mum)*

Mothers noted the general instability that characterised their child's friendships with mainstream school peers. For example, Abbie's mum said: *...but she quite liked coming round and we used to do some stuff, that seems to have gone off the boil..... (Abbie's mum)*

And later she says about another school friend:

*...but it's a very, bit of an on off relationship ... for a while they were thick as thieves and it was a really lovely relationship, I just don't know, I don't get the sense that they are doing as much together, ...(Abbie's mother)*

One mother also noted how the changing friendship patterns of non-disabled peers could have a detrimental impact on the social opportunities experienced by her daughter. Lucy's mum recalled how her daughter's female same-aged peers began to form smaller more discerning friendship groups in the later years of primary school and this resulted in her daughter being invited to less social events. While she was quick to add that this was the case for every child in the class, it was unclear whether her daughter was a part of any smaller social gatherings.

*Once they maybe got up to like Primary 4/5, you could see a lot of the kids had made like their wee groups em and then maybe Primary 5, the parties had lessened but then that was*



*the same with everybody, Lucy included, the whole class parties weren't happening anymore, it was just like pick a few of your best friends and go to the cinema and that, so it wasn't like suddenly she was not part of a party (Lucy's mum)*

The themes around children's relationships with non-disabled peers hinted at children in being generally quite socially isolated in mainstream schools. The protective role that peers took on towards their children, the gap that grew between them and the instability of these relationships were expressions of how their child's friendships with non-disabled peers were different from the relationships non-disabled peers had with one another. Furthermore, the quality of these relationships fell well short of what mothers wanted for their children and mothers were concerned about this aspect of their child's life and what it might mean for their child's future.

## **2. Child oblivious of social problems**

Mothers expressed many deep concerns about the quality of their child's social life. The second theme to emerge from mothers' narratives was their views about their child's experiences of friendships with peers. This theme was not straightforward. On the surface mothers tended to believe that their child was oblivious, untroubled by their lack of real friendships. However, there was a notable tension whereby some of the mothers' accounts did suggest an uncertainty or worry that, in fact, their child did want to have more of a social life, just as their mothers wanted that for them.

### ***Disinterest in socialising***

Many mothers said that their child had no apparent interest in socialising and were perfectly content and happy to play alone. However, this was associated with considerable unease for mothers. For example, Daniel's mum said:

*... he doesn't ask for it, he's happy to be by himself, he likes reading, he likes computing and TV, even though I control it, he cannot just be so, but he feels that he's happy put his music and be by himself, so but I don't, it's not healthy, so...(Daniel's mum)*

Lydia's mum also repeatedly said that her daughter was untroubled by her lack of friends and often chose to play alone, being perfectly happy in her own company, she said:

*I don't think she feels it, I think she's quite happy. She doesn't, when she says "Oh I just wandered about myself at playtime" and I think "Oh God" and but she's happy. She's*

*quite happy in her own company...[and later] ...but as I say she's not unhappy which is, if she was saying "Oh I don't have any friends to play with" then but it doesn't really worry her. So I think why should it worry me... (Lydia's mum)*

While Lydia's mum took comfort in the way her daughter was untroubled by her lack of social interaction, there was a sense that Lydia's mum was struggling to understand this area of her child's life. Lydia's mum described how when other young people were friendly towards her daughter, she did not reciprocate. Therefore, despite being presented with social opportunities, she apparently was not interested. Her daughter's disinterest in social interaction appeared to have become a worry in itself.

*...so she's not short of social activities to meet other people but she's just not interested...I remember taking her to the drama and standing in the queue and a wee girl from school came up and spoke to her "Oh hi Lydia, how are you? Have you done this before?" "Mmm" "What class are you in now at school?" Lydia told her and "Who's your teacher at school?" and Lydia told her and the girl is standing there but Lydia wouldn't, she never asked her any questions back. I said "Did you not want to know" "I don't want to know her teacher" she wasn't interested, and it's not that she doesn't ask questions, cos she does, ... she can ask questions, I just remember listening the girl asking all the questions and I'm waiting and waiting for her to ask some questions and I end up talking to the wee girl and I spoke to her when we got home, I says "Why didn't you ask" "Oh I don't know, I don't want to know who her teacher is", well, at least you're honest! Em, but it's aye, sometimes, she just doesn't care, so, that's it, it's not that people don't try or she doesn't have the opportunity to be social, she just doesn't care... (Lydia's mum)*

Other mothers also described feeling bewildered by their child's disinterest in socialising with peers and their seemingly blasé attitude to others, as their behaviour was at odds with their expectations of young people their age. Such expectations often originated in their observations of typically developing siblings.

*Mary [older sister] sometimes says to him, "Henry that's not a friend, a friend is somebody who you have over or" ...he's not interested in having anybody over, which I do find a bit weird to be honest, he just doesn't seem to need to have people come round for him. (Henry's mum)*

*.... Em so he doesn't seem to need people, you know, the way Mary does, to have people coming round after school. He doesn't really need that, or doesn't seem to need that. I don't know whether that'll change, em, but although he gets along well with everybody in the*

*class, but he never, I'll say do you not want to invite anybody over, "no", I don't really get it, but, anyway, maybe it will change, he's more interested in girls right enough, he's girls mad, they'll walk past and he'll go "hey she's hot" and all that, laughs. ... (Henry's mum)*

The above quote suggests that, like Lydia's mum, Henry's mum was struggling to understand her son's disinterest in social contact. There was a hint as well that she was uncertain about her own interpretation of her son's behaviour, as she said, "he doesn't really need that, or doesn't seem to need that".

Many mothers had observed then that their child with Down syndrome was apparently disinterested in socialising. This was a worry in itself as such social indifference was not seen as healthy, normal, or ultimately what mothers wanted for their child. Thus, often mothers believed that their child's distance from peers was as much to do with their own disinterest in socialising as a difference in interests and abilities.

Tension arose when it transpired that it was not as straightforward as an outright disinterest for many children. For example, in the quote below, Lydia's mum recognises that her daughter does want social contact. However, she felt that her daughter had slightly different expectations of social interactions that were off kilter from those of their same-aged peers. The difference between the expectations of their child and their peers seemed to centre on the degree to which an interaction involved two-way communication and mutuality.

*She talks a better game about having a friend and doing things with a friend than she actually does. She's always wanting somebody to come over and if somebody comes over to play, she wants them to sit and watch her dance like we all have to do half the time but she thinks, she's not quite got that you have to kinda come and go and do what other people want sometimes. Em, just the kinda social side of things, as I say, I feel she struggles a wee bit. (Lydia's mum)*

A similar idea was expressed by Abbie's mum, who suggested that her daughter's social style was more suited to the uncomplicated 'in the moment' and less verbal interactions of young boys. As when she talked about the gap between her daughter and her peers, Abbie's mother appealed to gender differences in social development.

*...whereas the boys are much more kind of, because they are not so much about words by and large at that age, they can just get on with it, so, they can do that, they can be more interested in her for a minute, say she's got something she's interested in, they'll have a*

*wee chat and engage with her about that and then wander off and do their thing, and in a way Abbie's quite like that, as well...(Abbie's mum)*

The incongruence that Lydia's mum saw between the interaction sought by her daughter and her mainstream school peers was also associated with her daughter seeking to interact with adults instead of same same-aged peers. This may be because the interactions adults provided her with the interactions she wanted or because she was able to have interactions with adults, while those with same-aged peers were trickier. Lydia's mum said:

*...she'd rather go to an older child or an adult for company as to go to her own kind of peers. Because an older child or adult is more likely to do what she wants them to do and play along with her whereas other kids her age expect more of a kinda interaction I'd say. (Lydia's mum)*

*em she's always keen for the helpers, you know the older girls who help me, she's keen, she's more friendly with them than she is with anyone else in the class, but they'll listen to her stories or whatever or do whatever she wants them to do, em, I don't know, that's something we'll try to work on...(Lydia's mum)*

Lydia's mum saw this as something to work on as she wanted her daughter to enjoy friendships with her same aged peers.

### **Satisfied with siblings friends**

The mothers of daughters who had same a same gender sibling often implied that their child with Down syndrome saw their sibling's friends as their own. For one mother, this provided some explanation of her daughter's social indifference with regards her own school peers.

*...but she's quite happy just sorta kinda mingling with them. I think she sees them as her friends as well. (Sophie's mum)*

For another mother, this simply provided comfort that her daughter was experiencing positive social relationships and did not notice that she was lacking her own social circle.

*...with Kate and her friends coming over and you know they're up there doing their hair you know from like say 14 and up, Lucy's been in there with them, doing it all, the music, oh gosh, she could sing you any song that's on the MTV or the box or something, so she's grown up with that having an older sister and her friends over. (Lucy's mum)*

### ***A growing awareness***

A contrasting narrative was expressed by one mother whose daughter was 13 years old. Fiona had attended a mainstream primary school up until primary 6, when her family had decided that it was the right time for a move to a special school. This decision was based on her mother noticing her daughter's increasing social isolation and increasing awareness of it.

*Yeah, I think she did, probably up to, I think primary six, she probably noticed, you know more of a social difference, em, and I think she enjoyed primary 7 in [special school] more than she enjoyed primary 6 at [mainstream primary] but em, kind of socially, and she certainly seems a lot happier to go to school now, em, the bus comes for her and she's delighted to run out to the bus, so it's good...(Fiona's mum)*

In summary, mothers had an acute sense of the ways that their child's relationships and interactions with peers were different from those among non-disabled children, and were very concerned about it. When addressing these social difficulties from their child's point of view there was a tension between, on the one hand, believing their child was untroubled and not interested in socialising, and on the other hand, recognising that their child did ask for and want social contact. Therefore, it would seem that children did desire social interactions, even though they appeared to find them difficult. One strategy children perhaps used to overcome their difficulties with interaction was to seek out the company of adults and older individuals, as they were more supportive of their needs. Although not explicitly said, some mothers' narratives implied that their children's feelings about their peer relationships was an area of their child's inner world they did not understand. Therefore, the mothers worried whether they were dealing with this social issue appropriately. Furthermore, for some mothers, there was sense that they feared this was an issue that was bubbling under the surface. For the moment though, many mothers talked about the ways they tried to alleviate the problem by managing their child's social world, and the challenges this entailed.

### 3. Mum managing the social gap

#### *Providing social opportunities*

Mothers were driven to provide for their child's social life and fill the gap that was missing in their child's life. Two mothers' talked about how they felt they had to push for social contact for their child.

*... they are not those that offer, can Daniel come and play with my daughter, they never ask us, they never phone, I phone, I phone, I'm going to take Daniel to the cinema, can I take Lisa, or it's happened that eh when I phone, ah they are going to the cinema today, Daniel can come, but I feel it's more one direction than two, it doesn't happen as much as I wished it would. (Daniel's mum)*

The responsibility felt by one mother to act in place of her child for his best interest is illustrated by the quote below where Daniel's mother says she has to "be his voice".

*... I say doesn't voice what he wants like the other children, I'll play, can I do that part, he doesn't, so I need to be his voice and I need to, but you know, I haven't seen much happen there anyway, so, it's always, you know, because he's not the one, he doesn't voice much what he want and things. So, it's not always naturally that people accept him, so em... (Daniel's mum)*

Pushing for social opportunities was something that mothers often did not feel comfortable doing, but they did so because they believed it was in the best interests of their child.

*Cos sometimes, I think I have to kinda do what I think is best for her, no I don't like phoning up people and saying, does your wee one want to come over or whatever, em I've done it a couple of times and, ...but I don't like doing it all the time but I kind of do it for her but as I say maybe they're kind of holding back a wee bit, but nothing too bad ... (Lydia's mum)*

One mother also spoke about the effort she put in to provide a rich social life from family and her own friends as a substitute for her daughters own friends. However, she later said that this was becoming more difficult as her daughter became older and was just beginning to think about how she could create more social opportunities for her.

*I think because there's people roundabout Lucy all the time, like, with my friends and like kinda their kids and the family, I think for that reason, she's never really questioned, why*

*don't I have millions of friends, why can't I go out to play on my own, I've always made sure during the holidays and everything, there were friends over or we were out or we were at friends or I would take her friends swimming, I've always, it's hard work as well sometimes, because you're always have to do, but I've always kinda tried to do that, so that she didn't feel... (Lucy's mum)*

*... I just didn't need to, I had a circle of friends and there was young children and everything, em, now, I kind of question, as Lucy's getting older, what is out there and I have been Googling a lot lately because I feel she needs maybe, as she's getting older now, more kinda friends, sorta groups sort of things, you know. (Lucy's mum)*

When family and close friends were a greater distance away this was keenly felt, as it was more difficult to provide an opportunity for children to feel part of this extended social network.

*...because of that it's kind of quite hard to generate the same kind of opportunities to, for her to spend time with people, you know, so ideally, you know, our friends kids would also be my friends kids, my kids friends, ...and that's one of the things I really miss, I think it'd be much easier I had that, because family friends are the easiest ones, they're the oldest ones and the most relaxed ones, I find managing her play dates can be quite trying...(Abbie's mum)*

In summary, mothers were very conscious of the difficulties their child had with social relationships and were pained by their child's lack of friendships with non-disabled peers. Mothers did make efforts to provide for their child in this respect, even though they experienced challenges in doing so.

Mothers' views of their child's social relationships provided a backdrop for their beliefs regarding their child's awareness of Down syndrome and sense of difference from non-disabled peers. Mothers' narratives in relation to their child's awareness of Down syndrome were complex and fraught with tensions. The ways that families approached the issue of telling their offspring about Down syndrome were far from straightforward. Similarly, mothers' views about their child's awareness of Down syndrome were often contradictory. What was clear, however, was that the mothers found it difficult to deal with the stigma associated with their child's disability, and with their struggle came the wish to protect their child as much as possible.

### 6.3.2..Section 2: Families' Disclosure of Down syndrome and Child's Understanding

The first part of this section will begin by presenting the results from two mothers who had told their daughter's about Down syndrome. Then, the results relating to the remaining mothers who had not directly broached the issue will be presented in the second part of the section.

#### 6.3.2.1 Part 1: Results from two mothers who had told their child about Down syndrome.

Table 35 shows the themes that emerged from the narratives of two mothers who had told their child about Down syndrome.

**Table 35: Themes from two mothers who had told their child about Down syndrome**

1. Family telling	2. Child's understanding	3. Anxieties about the future
Getting in there first	Awareness of Down syndrome- an empty label	Noticing stigma...?
Downplaying Down syndrome	Noticing facial similarities	
A normal difference		
Not central to child's identity		
Using social opportunities		

#### 1. Family telling

##### *Getting in there first*

Both Lydia's and Lucy's mother explained that they had decided to tell their daughters about Down syndrome because they were worried that they would hear it from someone outside the family home and be upset or confused. Rather than risk that happening, these mothers preferred to take control by 'getting in there first'.



For example, Lydia's mum said:

*I think I first introduced the word maybe about 2 or 3 years ago, she was about 7... I just brought the word, because I didn't want her to hear it and be like "No I don't. I don't know" so I introduced the kinda word and then a wee bit more... (Lydia's mum)*

Similarly, Lucy's mum said:

*... I only mentioned the words Down's Syndrome a few years back to Lucy and the only reason I done it then was because I was frightened she heard it from someone else and didn't understand it, so I sat her down and I went, I just told her when she was a little baby she was born with this em thing and it was called Down's Syndrome, ... (Lucy's mum)*

### ***Downplaying the implications of Down syndrome***

For both these mothers, the information they passed to their child about Down syndrome stayed within tight limits. Both mothers introduced the words 'Down syndrome' and identified it with learning difficulty, but it was clear this was as far as they wanted to go in their explanation. Further, these mothers were keen to downplay the importance of Down syndrome. For example, Lucy's mother said how she went on to qualify her disclosure of Down syndrome to her daughter:

*...but, it wasn't very important, she didn't need to know much, it just meant it was a wee bit harder for her to learn things... (Lucy's mum).*

Similarly, Lydia's mum was keen to emphasise to her daughter that she would find it more difficult to learn things, but there was no boundary to her abilities. Like most parents, Lydia's mum was keen not to place limits on what her child was capable of. For example, she said:

*...you might need help and it'll take you a wee bit longer to maybe get a thing but there's no reason why you won't be able to do it, you'll just need to practice a little bit harder and concentrate, and what was it she said the other day, I'll just need to focus, I don't know where that came from, but she said "I'll just need to concentrate and focus" I said "that's right" (Lydia's mum)*

### **A normal difference**

Lydia's mother explained how she chose to tell her daughter about Down syndrome. Her strategy was to couch Down syndrome in terms of other individual differences that exist among people.

*...but I explained to her, as I said, my nephew has asthma, I've got diabetes, so we just said you've got something a wee bit different, it makes things a wee bit trickier for you,  
...(Lydia's mum)*

Lydia's mother's strategy to explain Down syndrome to her daughter suggested that she distinguished between Down syndrome, a stigmatised social identity, and learning difficulty. For Lydia's mother, learning difficulty did not appear to engender the threat to her daughter's self-esteem that disclosure of the social significance of Down syndrome did. By couching her daughter's difference in terms of more socially benign individual differences, Lydia's mum appeared to have sidestepped disclosing the social meaning that Down syndrome holds. While Lydia's mother was painfully aware of this reality, she did not want her daughter to feel different. Lydia's mum indicated that she had told her daughter as much as she wanted her to know, in the kindest way. There was however a sense that she was anxious about how the family would deal with the issue in the future.

*...I think we've always treated her as much as possibly normal as possible so that she doesn't feel different, but the reality is she is, so, we've told her that in the best way we can that everybody's, not everybody's the same anyway, so, and just tried to explain it...and probably as she gets a bit older we will go a bit more depth with it but I'd say that's kinda how we've coped with it (Lydia's mum)*

### **Not central to child's identity**

Both mothers were also keen to make it clear that Down syndrome was not considered an important issue in the family home. Lydia's mum said the following:

*I mean, we don't, I'm sounding here as if we talk about it all the time but we don't, it's, Lydia is just Lydia and that's really always just how I've kinda, I've never kinda ventured down...(Lydia's mum)*

Lucy's mum emphasised that Down syndrome was only an incidental element of her daughter's identity within the family. She felt particularly strongly that she did not want

Down syndrome to be a dominant or defining feature of her daughter. This appeared to be linked to feelings of resentment that stemmed from painful past experiences of how such a social identity had been ascribed to her daughter.

*But other than that, that's the only time it's been mentioned. But I don't, I've never focused on it, I've never made it a big deal, I've never wanted it to be who Lucy was. She always has been and always will be Lucy, she just happens to have Down's Syndrome [and later] ...when you have a child you don't get to look in a crystal ball and see what they're going to look or be like but if you have a child with Down's Syndrome, people assume they're all going to be kinda be the same and look the same because that is what society kinda does think. You don't need to see that when you've got your wee person, you don't need to see that, you just learn that as they grow up because you find out very quickly that they don't grow up to be that person with Down's Syndrome, I look at Lorna [older sister] and Lucy and without a word of a lie, hand on heart, I see my two girls as the absolute same... (Lucy's mum)*

## **2. Child's understanding**

For both Lydia and Lucy's mothers, their beliefs about their child's understanding mirrored what they had told them and wished them to know.

### ***Knows terms, but just empty labels***

Lydia's mother described that her daughter knew the term Down syndrome and that having Down syndrome made it more difficult for her to learn things.

*...now she'll say, she knows herself, she'll say "Oh maths today but, because of this Down's syndrome, it's tricky". (Lydia's mum) She knows it's there and as I say she'll explain sometimes, she'll say "Oh they mental maths, I couldn't do it mum, you know how I've got the Down's syndrome, oh it's hard" (Lydia's mum)*

However, she believed Lydia was oblivious to any differences between her and her peers. She described an incident in which her daughter struggled in a sports day event. While this was painful for her to watch, she believed that her daughter was unaware of how her performance differed from her peers. Lydia's mum went on to describe how, in the same event the following year, Lydia had come up with a handy solution to the problem. In this

example, Lydia's mum suggested that Lydia was blissfully unaware of the social embarrassment that many would feel in such circumstance.

*...but och at sports day it was a surprise, she ended up winning this year because they did the sack race so Lydia just carried the sack and ran and she won so that was great! But the year before it was the three legged race and it just about broke your heart. She's got enough coordination just to get herself going never mind coordinating with somebody else! But she doesn't, like she wasn't embarrassed that she was running herself holding the sack and everyone else was in it, she didn't think "Oh that's not right" She said "I won" and I said "Aye right you did!", it's the first time she's done anything like that. So I don't know that...it doesn't bother her. (Lydia's mum)*

Lydia's mum described how her daughter knew about Down syndrome but did not feel different from her mainstream school peers as a result. She believed that this was because of the way it had been explained to her and the way the family had been careful not to make her different. Therefore, it appeared that Lydia's mum believed her daughter's understanding was a reflection of how the family had handled the information.

*...but she knows to a certain extent but, and we've never made her different, so, she, I don't think she does, I don't know, I don't think she does. She knows it's there but I explained it that everybody's got a wee something different and there's other kids get out the class, with no particular problems, but have to get taken out for extra support so... em I don't know that she sees that, to be honest. (Lydia's mum)*

Lucy's mum was resolute in her belief that her daughter did not feel different and stressed that she did not want her to.

*...she doesn't see herself as any different whatsoever. She doesn't see herself different from me, different from Kate, no, she doesn't at all, but I wouldn't want her to, I don't know. I'll ask you a question, do people with Down's Syndrome see themselves as different? Do you know that? Maybe some wouldn't, some would, right. Lucy at this point, no absolutely doesn't see herself as any different... (Lucy's mum)*

Just as Lucy's mum did not wish to view Down syndrome as a significant part of her daughter's identity, she believed her daughter did not view Down syndrome as important either.

*No, she just said "Oh yeah, whatever" and I'll say to her every now and again "Do you remember the word that Mum told you when you were a wee baby that you have?" and*

*she'll go "Yeah" and I'll go, "What is it?" "Eh, Down's Syndrome"... and if we watch something on TV now and there's something with Down's Syndrome, I'll go look, Lucy look, "See that girl there she has Down's Syndrome" and she'll say "Oh yeah". She's not "Oh does she!" She doesn't give a monkey's eh at all. (Lucy's mum)*

### **Noticing facial similarities**

However, while these mothers did not think their child has any sense of being different from non-disabled peers, they did describe incidences where their daughters had identified themselves as similar to others with Down syndrome. For example, Lydia's mum said:

*what I have noticed, em...a few years ago when we were on holiday, and there was another wee girl and we were in a holiday camp and Lydia spotted her and she said "That wee girl's the same as me"...Aye and she seen this wee girl and she's done it with, a wee while ago, there was a DVD on the telly and there was a Down's child on it and she homed in, so that was quite interesting. I'm saying "Stop pointing" but she like "But that wee girl is the same as me" and I'm saying "Well stop pointing" and then the mother drew me a dirty look! But I was quite chuffed that she'd, quite impressive that she noticed that! So she can see it I would say because she's done that a couple of times. (Lydia's mum)*

Lucy's mother told a similar story:

*What she did do but, we were out at [local shopping centre] and there is a young girl with Down's Syndrome works in Primark and we were walking through [local shopping centre] and this girl's walking towards us and Lucy almost burst a blood vessel "Mum! Mum! Mum! She looks like me, she looks like me" and I said, "Oh, so she does, she's got Down's Syndrome as well, [whispers] but you're prettier" Just to add a wee bit ...cause I'm her mum. And then she went "Oh" and then two seconds later, shwwwp, it was out of her head and that was her, she wasn't interested. But I think she, recognised that this person, kind of, she recognised herself in this person, but, other than that, no... (Lucy's mum)*

## **3. Anxieties about the future**

### **Noticing stigma...?**

The separation of Down syndrome from related social stereotypes came under threat for Lucy's mum by experiences of stigma. Her daughter was frequently stared at and she was acutely aware of it. The staring the family experienced brought to the fore a tension

between the social reality of difference and uncertainty over how she would cope with it in the future. Further, that her daughter was regarded by others as 'different' seemed to present a personal conflict for her.

*Well it can be because how you look is how people look at you. They're looking at how you look and as I said, Lucy is very aware, she's asking me why are people looking at her. When she's older, maybe I should be saying to her, no I would never say "People are looking at you because you have Down's Syndrome, because then I would need to say that people with Down's Syndrome, and I don't want Lucy to think that she does look different from people. We're all different, I'm different from you, I'm different from my neighbour, I mean we're all different, there's no two of us the same. Maybe when she's older, obviously I would say to her but as she gets older the staring is going to get much more annoying to her. Sometimes she doesn't notice it, it's just when it's in her face. (Lucy's mum)*

To summarise, Lydia's and Lucy's mothers described how they had told their daughters about Down syndrome. However, they had given the bare minimum of information, in order to protect their daughters' feelings. When asked about their child's understanding, they reported that it mirrored information they had provided.

### **6.3.2.2 Part 2: Results from mothers who had not directly broached the issue of telling about Down syndrome**

The remaining mothers described how they were open about Down syndrome around the home, but had not addressed the issue directly with their child. The narratives of this group of mothers were particularly complex and contained many tensions and contradictions. Table 36 shows the three themes that emerged from their narratives and the structure that will be used to describe them.

**Table 36: Themes from mothers who had not directly broached the topic of Down syndrome**

1. Family telling	2. Child's understanding	3. Uncertainties
Don't hide it, waiting on questions	Don't engage with Down syndrome	Some signs of awareness
Using natural opportunities	No sense of difference	Asking questions
Not making a big deal	Never treated as different	Anxiety about future
	Never asks	
	Unrealistic ambitions	

## 1. Family telling

### ***Don't hide it, but waiting on questions***

These mothers described how they did not hide Down syndrome from their child and mentioned the words around the home, but had not committed themselves by sitting down and talking about Down syndrome with their child directly. There was a general feeling that mothers did not want to impose talk about Down syndrome on to their child, and they described how they preferred to wait and let their child's awareness grow naturally, according to their child's own developmental trajectory. Henry's mum and Harry's mum describe their thoughts on the subject:

*...no we don't really hide anything from him, we tell him, you know you've got Down syndrome? But he doesn't, it's as if, he doesn't know what that is and the only other thing I'll say to him is, that's why sometimes you find your homework quite hard. I don't what to push it towards him. (Henry's mum) So, yeah, I mean I always talk about, I mean I don't hide, you know, I don't sort of eh hide the fact that he has Down syndrome or sort of talk quietly about it or anything, I always mention the words down's syndrome to him and yeah, I mean think he's starting to eh, he's not got to the point of asking questions about it yet, ... (Harry's mum) Em, no I think we just sort of try and keep it as open as possible, any opportunity that I do have to talk about it I will, em, but yeah, I've not really sat him down and I haven't sat him down for a big talk or anything yet, just kind of trying to try and do it*

*naturally as we go along sorta thing, but as I say he's just not got to the stage of asking questions yet about that,...(Harry's mum)*

The preference to wait for their child take the lead was strong. Mothers frequently described waiting on their child to ask questions. Below Henry's mum described her family's position:

*...but you know we do have conversations about, should we sit him down and say this to him and we just keep waiting for situations to come up, for him to ask the questions and then we can answer them. (Henry's mum)*

The wish to wait on their child to ask questions perhaps stemmed from not knowing how to go about telling them about Down syndrome. However, mothers' narratives also suggested that for mothers telling their child about Down syndrome amounted to 'breaking bad news', and ultimately, part of them just did not want to do it. Mothers keenly felt the hurt that they believed such news would bring their child. Henry's mum went on to describe her struggle in dealing with the social difference that has been imposed on her son's identity. She appeared to believe that her son was blissfully unaware and preferred that he remain so, as she would really rather not disclose this part of her child's social identity to him, and would only do so if she really had to.

*...why should it be, but that's the difficulty, what do you say to your son, well you need to know that you're really different from other people, and other people think you owe it to him...why am I going to say that to him? Why would I, why would I, I don't know, it would just hurt his feelings, I don't see the point in that. If I thought I should do then I would, but I don't really think I should. But I will be honest with him, if he asks a question, then I will answer him. But, I just don't want to impose what I think on him, you know... (Henry's mum)*

Similarly, Sophie's mum equated telling about Down syndrome with causing hurt. Since she believed that her daughter was blissfully unaware of it, she perceived telling her daughter about Down syndrome as causing hurt unnecessarily.

*It's like an acceptance, em, but she's never ever asked and I've never actually sat down with her and says "Sophie you're different", because it doesn't bother her just now and I don't see why I should make her all confused or get her upset or you know...(Sophie's mum)*



### ***Using natural opportunities***

However, many mothers described being more inclined to use natural opportunities to introduce Down syndrome to their child, by pointing out others with Down syndrome on the television or in the local community. This seemed to be seen as a gentle and subtle way to introduce Down syndrome to their child. In some cases they also seemed to use this as a means of gauging their child's responsiveness to it.

*But we do, see if there is, it's like that, it's where Henry's saw somebody and said you know, he looks funny, Chris quite honest and will say, well actually he looks a bit like you Henry, and I'll do that as well, if that situation arose. You know there are some things about that, well you look a wee bit like that too, I'd say that. (Henry's mum)*

### ***Not making a big deal***

Mothers were also clear that, as a family, Down syndrome was not a big issue and they did not wish to make a big deal about it. Peggy's mum was keen to emphasise she treated her daughter with Down syndrome the same as her non-disabled sibling.

*Not really, I try to treat her just the same as Peggy, which I don't really know if that's the right thing to do or not, but em, so we don't really make a big deal about it. (Peggy's mum)*

## **2. Child's lack of awareness of difference**

In the main, this group of mothers believed that their child was not aware of Down syndrome. However, as the interviews developed, more and more elements of uncertainty and conflicting evidence crept in.

### ***Doesn't engage with the words 'Down syndrome'***

Both Peggy's and Henry's mum described how their child did not engage with the terms Down syndrome. For Henry's mum this seemed to present a bit of a puzzle.

*I don't really think it's an issue for her just now, em, I don't know if she's aware that she's different. We have spoken about it but I don't know if she's picked up on it (Peggy's mum)*

*And again, as I've said before, we've said before, Henry do you know you've got Down syndrome? And he just kind of looks at you, you know, told you what that means, that's why*

*it's a bit hard for you to do maths and stuff, he doesn't really take it on at all. Nope. I don't know why... (Henry's mum)*

Sophie's mum also described how the words Down syndrome held no importance or meaning for her daughter.

*Nope, never, nup. Eh we've mentioned Down's syndrome an she'll, she'll just look at you and go 'what?!' (Sophie's mum)*

### **No sense of difference**

Just as these mothers described how their child was not responsive to the words Down syndrome, they did not believe their child had any sense that they were different from others.

*...she's never ever says to me or Tania or Luke, I'm different. You know it's, she just sees herself as herself to be quite honest. (Sophie's mum)*

However, at times there were question marks hanging over their statements and anxiety relating to an expectation that this would change. For example, although Abbie's mum did not believe her daughter held any sense of difference, she was aware that her husband had reached a different conclusion. Abbie's mum believed that both she and her husband thought that an increase in her daughter's awareness was inevitable, the idea of which provoked considerable anxiety.

*Derek (child's father) thinks that she is slightly aware, he thinks she has some sense that she's different, that she gets frustrated because she can't do things other people can do, I don't know that, I don't think I have seen that, but, I think, you know...I suppose, we're waiting on for her to recognise it (Abbie's mum)*

### **Never treated as different**

Mothers emphasised that they did not see their child with Down syndrome as any different within the family context and that they did not wish to see them in terms of Down syndrome. They also believed that their child's lack of awareness of their difference was in keeping with their desired world view. Mothers often explained that children did not see themselves as different because they had never been treated as different.

*I don't know if that's because Sophie's never been treated different, you know, I've never made any exceptions eh although it was a struggle for her to walk, talk and bla bla, it was, she was treated the exact same as the other two... [and later] ...but see she's never ever been treated different either, she been brought up just, eh like a normal child,... (Sophie's mum)*

### **Never asks**

However, mothers did recognise that there were ways in which their child was treated differently. For example, many children attended a different school to their non-disabled siblings or were given different school work in their mainstream classroom. Many mothers described how their child had never asked any questions that would indicate they had noticed or were bothered by this. In some cases this was associated with slight bewilderment, as mothers' seemed to have expected their child to question these differences at some stage.

*Abbie's doing different work at school, and I don't talk to her about that, why she's doing different work and, but she never ever comments on it, so she never volunteers any information, anything that suggests that she recognises the difference. (Abbie's mum)em but she's never ever been treated any different, you know, although she went to a different school fae Tania and Luke, she's never even asked why don't I go to their school. (Sophie's mum)*

Many mothers had concluded that their child simply accepted the way things were and were therefore not driven to question it.

*She's just so accepting, eh, or if you dyed your hair, she'd only, but the thing is wi Sophie, she's never actually asked, "why do I go to a different school". She's just accepted...it's like a trust, I trust ma mum, whatever's...it's just, it is, just a total acceptance...(Sophie's mum)*

### **Unrealistic ambition**

Mothers believed that their child had no idea of the implications that disability had for their future. For example, both Harry's and Fiona's mum spoke with some concern about the unrealistically high career aspirations that their child had. This was also often taken as evidence of their child's lack of awareness of Down syndrome in general.

*...no I think he doesn't, I think he's, he worries me slightly that, well maybe it's a good thing, that he doesn't, but it worries me that he's got such ambition for what he's going to be able to do when he's older. Which maybe that's a good thing and maybe he will be able to do it at some level, no, I think he sees himself very much as part of the crowd and part of everyone else, you know. (Harry's mum) So, em, cos she's talking about the future and she's never said, oh I couldn't do x, y or z because em, I know that the school are maybe quite keen to sort of discuss em realistic things to do after school, she still wants to be a fashion designer, something in fashion might be, but I mean I think she doesn't really know that there's any sort of boundaries to what she could do... (Fiona's mum)*

### **3. Uncertainties**

#### **Some indication of awareness...?**

There was considerable tension in mother's narratives regarding their child's awareness of difference. While on the one hand, as the quotes above have suggested, they believed their child was oblivious to their disability and did not engage with the words 'Down syndrome', on the other hand, they described incidences or behaviours that indicated their child might be aware of something. Even so, there was a strong wish to keep waiting for their children to ask questions and more concrete evidence. Perhaps this reflected a strong desire to believe it was not an issue, because it was simply too painful for them to confront and present to their child. This seemed to be particularly the case for Sophie's mother. For example, Sophie's mum talked about how her daughter hides her face when passing young people on the street.

*...because I really don't know if Sophie knows there's something different em and then there's other times when you can be walking with her like that, if it's like a group of teenagers and she sorta kinda shuns, you know you think, has it been name calling or, I honestly don't know, but it'd be interesting, I mean I would love Sophie to be able to say to me, well I look different but...but see she's never ever been treated different either, she been brought up just, eh like a normal child... (Sophie's mum)*

The staring that Sophie and her family endured in the local community was a source of significant stress. Staring impacted profoundly on the whole family. Sophie's mother had to deal with the distress it caused her and Sophie's siblings, and the anger it understandably caused her to feel. It was also very painful for her to think about Sophie's awareness of it. When asked if staring was an issue for her daughter, she said:

*Em, if she really, if someone is staring at her and she starts to feel uncomfortable, say we're in Mc Donald's or a restaurant or whatever, it's just she'll start that, you know the rocking, that's her getting agitated and yer like sorta kinda looking round, right who's been annoying her, you know, and it could be someone in that corner and Sophie's caught their eye but they've not took their eye offae her. And then she'll just start acting up and it's a case uh we go. So, it depends how obvious the person makes it, but oh she gets stared at all the time, and I'm not sure if she's aware of it, she is aware ay it sometimes, but we're more aware of it...(Sophie's mum)*

Sophie's mum recognised that there may be an element of awareness in her daughter's behaviour. However this appeared to be too painful to think about, as she quickly downplayed her daughter's awareness by saying it impacted more on the rest of the family. Similarly, later in the interview, Sophie's mum again expressed the conflict within herself about her daughter's awareness. As soon as she reported that there might be an element of insight in her daughter's behaviour, she quickly reverted to the less painful conclusion that she is in fact oblivious.

*eh, I think she's aware that there's something, but she's never ever asked and I've never ever said because until she says to me, then I can sorta kinda you know, go on, but em I think she's actually oblivious to be quite honest. (Sophie's mum) But if it doesny interest Sophie, she just cuts off and does whatever, but no, it has been mentioned. But as I've says, whether it's right or whether it's wrong, I've no says to Sophie that she's different, because it's no bothering her just now, if she starts getting distressed or saying why am I different, that's different then, but I don't see to open, you know, but she's certainly never em felt herself, or she's never mentioned that different or nothing...(Sophie's mum)*

Abbie's mother described the frustration felt by her daughter in relation to communication difficulties and suggested that this may have triggered some awareness of difference, especially in comparison to mainstream peers.

*I think she gets frustrated cos she can't do things but she hasn't identified, well that's what I think it is, she's frustrated by, she knows that she can't do things that other kids her age can do, um, and she gets frustrated when she can't do it, like speech, if she can't remember something, she'll be telling you something and she'll forget the word for it, ... if she's telling you something she really wants you to know about, and she can't remember it, then she gets very frustrated, and then, you know, there's a big explosive reaction, and I think that's part of the, I think there's an element of in there, I can't do this, why can't I do this and*

*everybody, because she sees everyone around her...I mean, it's daft, I forget that, then I see, I hear all the kids in her class talking to their parents and I realise how wide the divide is, because I do kind of forget that Abbie isn't the norm, em, and so, her daily experience must be one of, where she thinks, there must be so much that's happening that she recognises she can't do...(Abbie's mum)*

### **Asking questions**

Later further tension arose as Sophie's mum began to question the logic of expecting her daughter to ask questions about Down syndrome.

*Nup, just in her behaviour but I don't know if Sophie can actually turn round and say, say to me, eh, mum am I different? Eh, I don't think logically, it wouldny come like that, it would be more like, I know it annoys her when she starts the shaking or em she's turning her head or sometimes I've even seen her just lying in the street and she'll just no get up, end of. But I don't know logically if she can turn round and say that, but I know by her actions that something's happened that's triggered this response, and this is her basically her letting me know, "I'm no comfortable, but I don't know how to tell you that I'm no comfortable" and just to basically take her outta the environment. But she done that for years, ...So, verbally, she wouldny say anything but by her actions, yep, yep, definitely by her actions. (Sophie's mum)*

*[and later] ...I had tae get a bigger pram for Sophie, cos, like that, if we were eh walking down the road em a comment or somebody stared and at the time, stupid me, I didny realise, I just thought she was acting up and acting the goat and all the rest a it, it wasn't until a couple of weeks sorta kinda passed eh actually I had to buy this pram to take Sophie the shop, cos she would just, lie on the street wouldny go, start picking and all the rest a it, so I'd say it was six that she started being aware of folk em staring, and that's when she was sorta kinda putting her hand over her face, but she done that for years, and I'd say it's only since about last year that she's actually stopped it....So although she's, it's no till you've says that to me that that's just niggled in there, em, so it is, it's been non-verbal communication wi Sophie and it's took me for as long to understand, you're no saying to me verbally, but non-verbally wi your actions, I'd say since about six. (Sophie's mum)*

While Abbie's mother for most of the interview seemed to believe that her daughter was not aware of Down syndrome, a tension similarly arose as she questioned whether Abbie

would be able to identify Down syndrome to an extent that would enable her to ask about it.

*But as we've never talked about it, not that we, well we do talk about it in that, I mention, but never talked about it in the sense that you have Down syndrome. It's, you're asking her, you know, she wouldn't be able, to, I mean I don't know, I do think, it's easier to, once something has a name, it's easier to identify it, I think, so it's possible that if we had named this, diff, if we had pointed out the existence of a difference, then it's quite possible she would have recognised it (Abbie's mum)*

Therefore, while at times during the interviews mothers were quite certain that their child was unaware of Down syndrome, they also expressed some doubts. For many mothers, their child's inner life was a mystery and they longed for some guidance on the issue. For example, Sophie's mum said:

*...but em, wi Sophie she doesn't really say a lot, and that's how sometimes I'd love to get into her brain, ... [and later at the end of the interview] Actually it'll be interesting to find, you know if they're, do they see a difference, cos, it would be great as a parent, em, to know because if they did find a difference, then you could gradually introduce it you know like into their life, ...(Sophie's mum)*

For Abbie's mother, uncertainty brought with it an anxiety that the family should have broached the issue by now and a sense of urgency. For example, Abbie's mother said:

*I mean we haven't talked about Down syndrome to her, and I don't know, I think I sort of think, oh my gosh, we should have done, we should have mentioned it by now,...we haven't actually, and I suppose what I'm thinking is, em, I suppose, now I think we should, now, I think probably now is, we shouldn't leave it very much later... (Abbie's mum)*

## 6.4 Discussion

Families' decisions regarding telling their child about Down syndrome were far from straightforward. Mothers were acutely aware of the stigma attached to their child's disability and, as a result, they were sensitive to the negative impact such knowledge may have had on their child's sense of self. Mothers described how they struggled between wanting to tell their child what they needed to know but remained fearful of saying too much and causing unnecessary hurt. Two mothers had told their daughters that they had Down syndrome. However, the explanations were limited to general accounts about learning disability and neither appeared to want to broach the social implications of Down

syndrome in terms of 'difference'. Instead, the significance of Down syndrome was downplayed or it was explained in terms of other socially benign differences that exist between individuals. The remaining mothers said they did not directly address the issue with their children but would mention terms associated with Down syndrome openly at home. They described waiting for prompts from their child, usually in the form of questions, and a strategy of disclosing information on a 'ready to know' basis. Again, it appeared to be the stigma attached to Down syndrome and their child's perceived difference that was at the crux of mothers' anxiety. Ultimately, all mothers were at pains not to disclose to their child that others might think of them as 'different'.

This finding is similar to that of Todd and Shearn (1997), in that the parents did not openly discuss their offspring's social identities in relation to disability. Todd and Shearn (1997) reported that diagnostic labels associated with learning disability and the social significance of them were hidden from their offspring, while in the present study mothers appeared to have separated the two aspects, feeling more able to discuss the former with their offspring. The 'toxicity' of a disabled identity described by Todd and Shearn (1997) seemed to be diffused by mothers in the present study by limiting their disclosure strictly to having a learning disability and downplaying the social significance of this. It was unclear whether mothers in the present study would ever have felt it was acceptable or appropriate to discuss the social implications of having Down syndrome and other people's prejudiced or stigmatised views.

The participants in Todd and Shearn's (1997) study were the parents of adults with intellectual disability. Perhaps as a result of their offspring's age, the parents described the social implications of their child's disabled identity in relation to the limitations it placed on their lives, in terms of employment, marriage and having children. Therefore, the parents in Todd and Shearn's study were concerned that undermining their offspring's belief that they could achieve these life goals would have a negative impact on their sense of self. Anxieties about the mismatch between their child's future employment aspirations and what the mothers felt they could do were mentioned by a couple of mothers in the present study. However, the main concern of the mothers of the children in the present study was with the growing distance from their non-disabled peers and attempting to manage their children's feelings of difference from these peers.



The remaining mothers described how they operated an 'open house' and were waiting on questions and guidance from their child. While they expected the issue to arise they believed their child had not reached a level of sufficient social awareness yet. Thus, for these mothers their lack of disclosure was because their child was not ready for such information. None of the mothers described avoiding the issue altogether or hiding Down syndrome from their child. This finding stands in contrast to that of Todd and Shearn (1997), who found that parents felt either their child's disability precluded any awareness of disability or that their child's lack of awareness was due to the fact they had chosen to hide it from them.

Cunningham et al. (2000) also reported that parents made a conscious decision about the extent to which they should discuss the issue of Down syndrome with their adult offspring. Their findings indicated that parents were sensitive to the cognitive ability (as indexed by a measure of expressive verbal ability) of their offspring and provided explanations of Down syndrome accordingly. To an extent, this finding fits with the narratives of the mothers in the present study, who all described being responsive to their child's needs. Similar to mothers in the present study, Cunningham et al. also reported that parents' explanations centred on impairment; the social barriers their child may face were rarely mentioned and the stigma associated with Down syndrome did not feature in parents' explanations. However, it is unclear if parents were attempting to hide negative social attitudes towards Down syndrome for their offspring or if it was simply a too difficult or painful topic to address. The pain caused to the parents in the present study by the growing distance of their children with Down syndrome from their non-disabled peers suggests that the latter may be a reasonable explanation.

Cunningham et al. (2000) also reported that young people with Down syndrome in their study elicited parental explanations by asking questions. This resonates with the way that mothers in the present study reported waiting on questions from the children to prompt them in providing information about Down syndrome. However, Cunningham et al. thought that there could have been individuals who had an awareness of their Down syndrome and wanted to find out more but lacked the verbal ability to ask the questions they wanted answered. Mothers alluded to the same point in the present study, with a number unsure of the ability of their child to ask questions about their disability. Therefore, while mothers feared disclosing too much too soon, they also worried about not disclosing *enough* to their child.

Consistent with the participants in Cunningham et al.'s (2000) study, many of the mothers in the present study also recounted occasions when their child had recognised that their facial features were similar to others with Down syndrome. The facial characteristics common to people with Down syndrome appeared to function as an important reference point for self-awareness of Down syndrome, for some individuals. Thus, in contrast to seeing one's difference from non-disabled peers, these individuals perceived their similarity to others with Down syndrome. Young people were generally reported to respond with excitement, perhaps because it was reassuring to see someone similar to them, so rarely seen in the community or represented in the media. Equally though, it may be a bit of a surprise to find a stranger that 'has your face', since we all think of ourselves as individuals and only tend to resemble family members.

Many of the mothers in the present study mentioned times where their child was stared at. For two mothers, the staring they experienced was particularly blatant, and upsetting for the whole family. Staring was a form of stigmatisation that appeared to threaten the distance mothers had placed between their child and the prejudice associated with Down syndrome. When their child noticed they were being stared at, mothers found it increasingly difficult to create 'cover-up stories', since they could not reveal the real reason for the staring without also telling their child that others thought they were distinctive and their disability was associated with social stigma.

The mothers in the present study also talked at length about their child's social relationships with non-disabled peers at mainstream school. The degree to which their child's social relationships were a concern for mothers was not altogether anticipated by the researchers. Mothers were deeply concerned about their child's social isolation. This finding underscores that the difficulties children with intellectual disabilities experience socialising may contribute significantly to feelings of difference. Further research would do well to focus on this aspect of children's early social lives, and explore how their awareness of how their communication and social abilities differ from their mainstream peers, as this may be critical to their developing sense of self.

In addition, mothers concerns about their children's relationships with their peers highlights that the social challenges experienced by children with intellectual disabilities changes as the developmental trajectories of themselves and their peers diverge. Children with an intellectual disability will develop socially and cognitively at a different rate from

many of their non-disabled peers and this is unavoidable. However, this should not be the end of the story; there are ways to help disabled and non-disabled children form authentic relationships with one another. Unfortunately, the mothers in the present study appeared to feel very much alone in their attempts to remedy their child's lack of social relationships, despite the fact that schools are well-placed to help to foster social inclusion, and could work in co-operation with parents to improve this aspect of children's lives.

The findings from the interviews also suggested that while, on the whole, mothers believed they were being responsive to their child's needs for information about Down syndrome, they were not entirely certain and doubts emerged. These doubts seemed to arise because mothers remained somewhat uncertain about their child's actual communicative abilities and their inner world. Thus the mothers did express some uncertainty and they were anxious about what the best course of action was in relation to talking to their child about Down syndrome. Many mothers commented at the close of the interview that they felt guidance in dealing with their child's developing identity as someone with Down syndrome was absent and it was this that, at least in part, motivated them to take part in the study. Indeed, on the basis of the information provided to mothers when recruiting their child to take part in the study, some mothers talked about the value of the pictorial approach used with their children as a potentially useful method for gaining insight into their child's sense of self. The next chapter will bring together the findings from the mothers' interviews and those from the experimental research with their children in a final discussion.

## **Chapter 7: Main Discussion**

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The main purpose of this chapter is to look across the main findings from the quantitative studies and the qualitative study. It will be argued that, while there may be alternative interpretations of the results, the views expressed by mothers' contrasted with the responses obtained from children on the experimental tasks. This chapter will discuss these contrasting accounts of children's awareness of Down syndrome and stigma. The strengths and limitations of this research will then be discussed, before going on to consider the implications for policy and practice.

### **7.1 Main findings across both the experimental and qualitative studies**

The results suggested that, as a group, children with Down syndrome were just as aware of Down syndrome and held similar negative attitudes towards photographs of others with Down syndrome as their non-disabled same-aged peers. Firstly, they showed a preference to interact with non-disabled children over children with Down syndrome. Secondly, they chose to self-identify with others who did not have Down syndrome. Thirdly, children held views about photographed children with Down syndrome that were negative. Children with Down syndrome appeared to be more negative about others with Down syndrome than non-disabled participants. Fourthly, whilst the participants with Down syndrome proved resilient and reported a positive view of self, they were not as positive about themselves as the non-disabled participants.

The mothers who were interviewed mainly reported that Down syndrome was not salient to their child and did not hold any particular meaning for them. Many mothers described waiting on their child to take the lead in discussing Down syndrome, but since their child had never asked questions, the topic had not been broached in detail. There was a sense that they were reluctant to talk about it until they were absolutely sure their child was ready and the stigma attached to Down syndrome played a big part in this reticence. Mothers reported that their children were not aware of their stigmatised position in society. A minority of mothers had broached the subject of Down syndrome with their child, but only in terms of the associated learning difficulties. These mothers felt that although their child was aware of their disability, it was of no importance to them. Nevertheless, mothers were

deeply concerned about the quality of their child's social relationships with mainstream peers. Mothers described how they witnessed an increasing distance between their children and their mainstream peers, which resulted in their child becoming more socially isolated as they grew older. Mothers tried various means to bolster their child's social life, since it was far from what they wanted for them.

## 7.2 Contrasting views and past research

The mothers' view that their offspring were not aware of the stigma associated with Down syndrome is similar to the findings of Todd (2000) and Todd and Shearn (1997), who both reported that families and care staff also believed that adults with intellectual disability had been successfully sheltered from an awareness of the stigma associated with their disability. In addition, Todd (2000) also believed that the students in his study were unaware of the negative social views associated with their special school and that many appeared unaware of their disability. In sum, the accounts of mothers in this study were in keeping with the findings from previous research with young people with an intellectual disability. The views collected from children themselves in the present study, however, appeared to challenge such accounts.

There was a clear contrast between mothers' accounts and children's responses on the experimental tasks, with regards to whether the children were aware of Down syndrome and that it is viewed negatively in today's society. Most mothers thought that their child was unaware of Down syndrome. While a few mothers thought that their child was aware that Down syndrome exists, they believed their child's awareness was superficial and limited to the learning difficulties associated with it. All mothers felt that Down syndrome held very little significance for their children. By contrast, the responses of children themselves showed that they were sensitive to whether photographs depicted others with or without Down syndrome and they clearly discriminated between the two. Further, the children's responses indicated that they evaluated others with no disability more favourably than others with Down syndrome (Preference task and Adjective task results).

With regards to children's views of *self* in relation to disability and stigma, the picture is less clear. Mothers believed that their children viewed Down syndrome as being personally irrelevant and were unaware that they were stigmatised because they had Down syndrome. Whilst a minority of mothers had informed their child that they had Down syndrome, this

was only in terms of the learning difficulties they experienced. Children themselves showed that they did indeed have positive views of themselves in the Adjective task. It could therefore be argued that children's views of self did not encompass a stigmatised self, associated with Down syndrome, and that mothers' beliefs were consistent with the responses of children in relation to their experiences of self.

Whether one accepts the argument that Down syndrome was not personally relevant to the children who participated in the study hinges on how the results of the Self-identification task are interpreted. The self-identification task was clearly the most direct attempt to examine children's self-awareness regarding their Down syndrome. The overriding majority of children identified themselves with the photograph depicting a child with no disability. Whilst it was noted in section 5.3.8 that there were difficulties with interpreting this result, it was argued that while, on the surface, participants' responses on the task indicated they did not think of themselves as having Down syndrome there is another possible interpretation. Only five out of 27 participants identified themselves as having Down syndrome and, considering this result in the context of the findings of the other tasks, this suggests that participants chose to identify with typically developing peers and not those who have Down syndrome, and that they did so because this is a more socially valued identity. This interpretation is consistent with similar findings in the area of developing ethnic identity in children (Spencer and Markstrom-Adams, 1990). In addition, it should be recalled that the participants with Down syndrome were less positive about themselves than the non-disabled participants. It is acknowledged, however, that further research would be required to clarify this issue further.

### **7.2.1 A different method of enquiry**

Mothers spend time with their children in a variety of contexts, both at home and in the community. Thus, the finding that the mothers' did not perceive their child to be at all aware or concerned about Down syndrome does seem surprising in light of the experimental findings. It could be argued that the reason for the stark difference between the perspective of the mothers' interviewed and the responses of the children in this study perhaps relates to the anxiety felt by mothers around the place disability should have in their child's identity. Mothers expressed considerable anxiety in relation to their child's experience of disability, stigma and their thoughts regarding whether they should inform their child about Down syndrome. It is plausible that mothers' anxiety clouded their view

of their child's awareness. Perhaps the sheer degree to which mothers' felt the stigma attached to their child's disability made facing the possibility that their child may also be aware of it just too painful. During the interviews mothers' intimate knowledge of stigma and sensitivity to how they thought 'feeling different' would impact upon their child came through strongly. In addition, it was also clear from the interviews how unprepared mothers felt about dealing with this issue. They described a fundamental worry that if they brought up the topic of Down syndrome with their child it may be the wrong time or wrong thing to do, causing their child harm or upset. Again, these uncertainties, associated with high degrees of worry, may have obscured mothers' perceptions of their child's growing awareness.

The reluctance of mothers to talk about Down syndrome with their child echoed findings reported by Todd and Shearn (1997) and Todd (2000). In these studies both school staff and parents reported being fearful of causing upset to people with intellectual disabilities by exposing them to any information about their disability, partly because they perceived the stigma of it to be too great.

In the course of carrying out his ethnographic study, Todd (2000) spent a considerable amount of time with students in many different contexts, on a one-to-one basis and in the company of teachers. Given the proximity of the researcher to the young people in this study, one would expect that if young people had demonstrated an awareness of their disability then researcher would have been privy to it. However, Todd (2000) reported, in agreement with the school staff, that students were oblivious to their disability and any social meaning it conferred. Whilst school staff and researchers care about the young people they work with, one would not expect them to have the same level of emotional attachment as their parents do. In other words, one would not have expected their judgement to be obscured by their anxiety surrounding the issue of stigma.

Many of the mothers in the present study were uncertain about their child's inner world. In some cases, mothers reported that their child did not verbalise their thoughts or feelings. Consequently, the contrast between the findings from the children with Down syndrome in the present study and the mothers' perspectives may be related to the way in which the experimental tasks in the present study allowed the children to communicate their views. The same explanation might apply to the views of significant others and findings obtained in previous research by Todd (2000) and Todd and Shearn (1997).

Perhaps one of the problems has been the emphasis on verbal communication. This is reflected in the way that many of the mothers' in the study reported that they were waiting for their child to ask questions about disability before disclosing information about Down syndrome. Further, previous research in the area has used a qualitative approach where the very object of analysis is verbal utterance. People with intellectual disabilities have difficulties with verbal communication, although their receptive communication abilities are often stronger than their expressive skills and this means that people will often understand more than they can communicate themselves. Therefore, people may not be inclined to talk about an awareness of disability or stigma. Furthermore, it is difficult to describe quite abstract constructs such as disability or stigma, especially when there is limited information available and few cultural reference points in one's environment to scaffold one's understanding.

The methods used in the present study may have allowed children to express their awareness of the stigma attached to having Down syndrome, even if it was at a rudimentary level. Children's responses to the pictorial stimuli showed they could distinguish between those who did and did not have Down syndrome and that they held a negative affective reaction to Down syndrome. Therefore, it may be argued that, in the present study, the markedly different method of investigating the children's awareness of stigma from previous studies led to the different findings.

### **7.2.2 Reliance on verbal communication**

Care may need to be taken when emphasising the value of the tasks, insofar as they allowed the participants to express views that they may have lacked the ability to express verbally. The children's responses in the experimental tasks did show a relationship with their level of verbal ability, as measured by the British Picture Vocabulary Scale (BPVS-II: Dunn et al., 1997). Specifically, the degree of awareness shown by children was positively related to their verbal mental age. This finding is consistent with those of Cunningham et al. (1997). However, Cunningham et al. (1997) reported that a verbal mental age of 5 was necessary for an awareness of Down syndrome. Further, Cunningham et al. argued that young people's level of verbal understanding predicted whether their families had told them about Down syndrome.



The relationship between verbal mental age and awareness of Down syndrome was not clear cut in the present study. Children with lower verbal mental ages did show that they could discriminate between photographs of others with and without Down syndrome, and held negative feelings towards Down syndrome. While it is of course also likely that verbal ability may play a role in level of understanding of Down syndrome and stigma in children, it is argued here that it is also possible that the relationship between verbal mental age and task performance may be in part an artefact of the task procedures themselves rather than awareness per se. In other words, it is suggested here that the way that verbal mental age is related to children's responses is more complex and unlikely to be explained by reference to one factor.

### **7.2.3 A developmental understanding of social categories**

The findings of the present study also fit broadly with the developmental psychology literature on children's developing understanding of social categories, such as gender and ethnicity. This research emphasises that children may have a level of understanding of some social categories before they are able to express such awareness through verbal means. In late infancy (9 to 12 months), children can distinguish between faces by gender (Brooks-Gunn and Lewis, 1981). Katz and Kofkin (1997) found that infants as young as 6 months responded to faces of Euro-American and African-American people in a categorical fashion. Thus, this research suggests that children's inclination to categorise others according to visual facial cues emerges early in life and before they develop language.

The psychological literature also highlights that children's ability to deal with social categories verbally depends not only on a base level of cognitive capacity but also on how readily this information is provided in their social environment. For example, studies generally report that by 2 years old children can reliably verbally label themselves and others as male or female (Weinraub et al., 1984; Thompson, 1975; Katz and Kofkin, 1997; Golombok and Fivush, 1994). However, children's proficiency with race labels lags behind those of gender. It has been suggested that children learn to use ethnic labels correctly later than gender terms because, in contrast to gender, parents talk about ethnicity less often with their child, as it is less likely to arise (Katz, 2003). Therefore, in order to learn to talk about social categories, children need exposure to the relevant vocabulary. According to the interviews conducted with mothers in the present study they rarely discussed Down syndrome with their children or talked about disability. Therefore, it might be

understandable why the children in the present study were unable to verbally express their awareness of Down syndrome.

#### **7.2.4 Findings in relation to theory: A reflected self..?**

The findings of the present study suggest that many participants with Down syndrome had already developed a substantial awareness of the negative social attitudes attached to Down syndrome by eight years of age. If children do not find out about Down syndrome and the associated social stereotypes from their family and significant others in their lives, then how do they develop such an awareness?

Mead's (1934) notion of the development of a generalised view of 'other' might provide a helpful explanatory framework. According to Mead (1934), from a very early age, children play at taking on different social roles and then progress to play games where the relationships between different roles are appreciated. Through this process, children form a composite view of how society (in which they reside) views different social groups. Thus, even though children with Down syndrome may not follow this prescribed developmental process, there is no reason to believe that they do not engage in the same process of working out how the social world works and different social groups relate to each other. Moreover, children with Down syndrome are likely to have direct experience of how children with disability are viewed.

Another question that arises is that if the children with Down syndrome expressed negative attitudes towards children with Down syndrome and were aware that they belonged to this group, then how did they manage to view themselves in a positive light? Major and O'Brian (2005) suggest many different strategies are available to individuals to bolster and protect their self-esteem in the face of stigma. The very act of distancing themselves from the social category of the Down syndrome group may have served to boost their sense of self. Moreover, it is possible that they may have used different social norms in relation to themselves as compared to Down syndrome as a social group. The same social awareness that led to the children's negative views towards others with Down syndrome perhaps meant they were also aware of more positive social values that could be used to counteract stigma. In other words, awareness of more positive social values and norms might have helped individuals to reject discriminatory treatment. For example, values about fairness and whether it is right to judge people by how they look or because they have a disability. Even the youngest non-disabled participants in the present study showed they were aware

of such moral codes. Therefore, it may be that children with Down syndrome, alongside being aware of the stigmatised nature of Down syndrome in general, also hold the counter belief that Down syndrome does not necessarily make people any less as persons or mean that stigmatised treatment is deserved or right.

Goffman (1963) thought that at least some ambivalence towards the self was inevitable for an individual with a stigmatised identity. Children's awareness of stigma does raise questions as to whether they can uphold such positivity in the long run. Unfortunately, it is difficult to believe that belonging to a stigmatised group will have no effect on children's sense of self. The findings of the present study indicated that even though the children with Down syndrome reported positive views of themselves, they were not as positive as their non-disabled peers.

It is possible that the views expressed by children in the study did not represent their actual views, but rather their conformity to the views they assumed the researcher held. In other words, the children's belief that the researchers would hold negative views of Down syndrome might have driven their responses, rather than expressing their own views (Jahoda, 1972). An interesting twist to the design used in this study would be to find out if children altered their responses in the event of a researcher with Down syndrome or another visible disability carrying out the task procedure.

### **7.2.5 The findings from the non-disabled group and past research**

It was found that young children aged 5 to 8 years old showed a clear preference to share activities with non-disabled children compared with those with Down syndrome, were able for the most part to sort photographs according to Down syndrome, correctly identify themselves on the basis of not having Down syndrome and attribute traits according to a conception of Down syndrome that matched common social views of Down syndrome. These findings clearly indicate that these children responded to Down syndrome in a categorical manner.

These findings contrast with those of previous research investigating similar aged children's awareness of Down syndrome. Diamond and Hestenes (1996) asked children aged 3 to 6 years old who were enrolled in inclusive pre-school programs to describe photographs of unfamiliar children. The photographed children had a physical disability, a hearing or visual disability or Down syndrome. The researchers reported that while most children were aware of physical disabilities, fewer appeared aware of sensory disability

and none of the children made disability-related comments in response to the photographs of children with Down syndrome. Diamond and Hestenes (1996) concluded that the children appeared unaware of the facial characteristics typical of those with Down syndrome, perhaps because the features were too subtle for young children to notice. However, it is possible that the quality of the photographs used in Diamond and Hestenes (1996) study compromised their results, as they were black and white pictures taken from story books. Perhaps the lack of colour interfered with children's sensitivity to facial cues associated with Down syndrome or the pictures included other objects that took children's attention away from all but the most salient physical disabilities (i.e. the presence of a walking frame).

A study by Innes and Diamond (1999) suggests that mothers do not typically talk about Down syndrome with their child. In a storytelling task, the researchers gave mothers photographs of children with disabilities and encouraged them to talk with their child about them in any way they liked. The children in this study were also aged 3 to 6 years old. Innes and Diamond (1999) examined how mothers communicated with their children about Down syndrome and physical disabilities. In contrast to physical disabilities, they found that Down syndrome was not typically talked about by mothers and their children. Children made few comments and asked no questions about Down syndrome, similarly mothers did not mention it. The researchers suggest that the equipment (e.g., wheelchair, walker, braces) associated with physical disabilities are salient to children and also give mothers more to talk about with them.

Thus these studies suggest that young children would not be expected to be sensitive to the facial characteristics of those with Down syndrome. However, the few studies that have been carried out have sought verbal responses from the participating children. Therefore, a combination of the children's limited verbal skills and, because no one may have talked to them about Down syndrome before (Innes and Diamond, 1999), might have made it difficult for them to verbalise about this subject. Therefore, it may not have been that children were unable to identify the typical features of Down syndrome or did not notice that people with Down syndrome looked different. Instead, they may have found it difficult to express their awareness of such differences. In support of this contention, Diamond (1993) found that when children aged 4 years old were shown photographs of disabled and non-disabled peers and asked to show the interviewer who 'doesn't walk or run the way other kids do' and 'who doesn't talk as well as other kids do', they nominated children with physical disabilities and those with an intellectual disability. Therefore, these young

children showed that they were aware of physical and behavioural differences between their peers. The findings of another study by Diamond (1994) also suggested that children differentiate between their peers with physical and cognitive disabilities. The researchers reported that children aged 3.5 to 5.5 years old judged their peers with an intellectual disability to be less competent in cognitive, language and physical domains, while peers with a physical disability were viewed as less competent in the physical domain only. In line with Diamond's (1994) findings, the present study also suggests that children may be more sensitive to subtle differences in their peers' abilities than often given credit for.

The significance of the findings of such studies as these of course lies in their implications for children's real behaviour towards, and acceptance of, peers with disabilities.

Unfortunately, there is considerable evidence that preschool children with disabilities are often socially isolated and chosen less often as playmates by non-disabled children (Guralnick, 1990; Odom and McEvoy, 1988).

## **7.3 Methodological implications**

The methods used in the present study were unique in the area of intellectual disability and the aim was to build on the techniques used in previous child development studies. How did the methods fare in reality? This section will consider some of the strengths of the approaches used and then go on to describe some challenges that were encountered in the development of materials and weaknesses that were noted.

### **7.3.1 Strengths of methods: A non-verbal approach**

A non-verbal approach was chosen because it was hoped that it would tap into the views of a group of young people who have communication difficulties. Game-like tasks with pictorial stimuli were used because they required minimal verbal explanation and therefore the objective of the tasks would hopefully be apparent to participants. Moreover, the tasks did not require any verbal responses from participants and instead participants responded manually, by placing pictures into boxes. It was hoped that the tasks were physically and mentally engaging. Observing the children during data collection appeared to confirm that that the tasks worked well and, on the whole, the children engaged well in the sessions.

The findings suggested that participants held emotionally charged views about Down syndrome, as nearly all those with Down syndrome demonstrated at least some negativity

towards photographs of others with Down syndrome. Therefore, an added strength of the methods was that they tapped into an emotional issue for the children in a relatively unobtrusive manner.

The method used in the present study was substantially different from those used in previous studies. Previous research with young people mainly relied on self-report measures. In order to make the measures more accessible, researchers have often read them aloud to young people either in a group setting or during an interview style session (Crabtree and Rutland, 2001; Szivos, 1991; Szivos-Bach, 1993). Cooney et al. (2006) adapted a social comparison measure by adding pictures to aid comprehension. However, the measure involved the use of vignettes that were read aloud to participants. The qualitative studies by Kelly and Norwich (2004) and Norwich and Kelly (2004) used semi-structured interviews involving various idiographic techniques, while Todd (2000) adopted an ethnographic approach. Participants in all these studies were expected to give verbal answers. A significant strength of the present research was that it did not require the participants to say anything, although their responses were often accompanied by verbal utterances. The verbal responses did serve to increase the researcher's confidence that the participants were engaged in the tasks, but these verbal responses were not the object of analyses. Many of the participants in this study would have been unable to provide valid responses if the approach had required greater verbal skill, both in terms of procedural comprehension and better expressive abilities. Thus, the approach taken in the experimental work made the tasks accessible and engaging for young people who had a wide range of abilities.

### **7.3.2 Challenges encountered when developing the materials**

As was described in chapter 3 suitable photographs of children with Down syndrome proved to be very difficult to come by. This meant that developing the materials for the task took seven months. However, this was considered this time well spent, as it ensured the photographs to be used in the task were of high quality, which ultimately helped to elicit meaningful responses from the participants. The alternative would have been to settle for low quality photographs that either did not clearly show the face, depicted children showing a range of facial expressions, or children from different angles. All of these differences among the photographs could have potentially confounded the variable of interest in the study.

## 7.4 Limitations of study

### 7.4.1 Limitations of tasks

The aim of the experimental tasks used in this project was to measure participants' awareness of Down syndrome, whether participants saw themselves as a member of the social category and their positive and negative views of Down syndrome. While every effort was made to ensure that the tasks did measure the constructs intended, the difficulties of doing so were recognised.

Participants' awareness of Down syndrome as a social category was measured in the Sorting Task. The verbal instruction that accompanied the task asked participants to put each of eight photographs depicting children with and without Down syndrome into one of two boxes identified with either a photograph of a child with Down syndrome or with no disability, according to which each photograph was "most like". Sorting the photographs in this task was interpreted as demonstrating an awareness of Down syndrome. It was recognised that sorting the photographs according to physical similarity does not necessarily confer awareness of Down syndrome as a social group or an understanding of what Down syndrome is. However, noticing the facial features of Down syndrome and choosing to utilise them to categorise others does suggest that the features do have a social salience. Further research and comparisons of these findings with the findings of other tasks designed to measure similar constructs would help to strengthen confidence in the content/construct validity of the task.

The aim of the adjective task was to measure participants' evaluations of others with and without Down syndrome. In order to do this, participants were asked to indicate whether descriptors, represented by colour illustrations, applied to photographs of a young person with Down syndrome, a young person with no disability and themselves. Pictorial representations of the descriptors were used to help make the task more accessible for those with limited verbal skill. However, it is possible that this type of representation introduced some uncertainty because it is unclear if the participants interpreted the pictures in the same way, thereby introducing uncertainty about what constructs were actually being measured. For example, the illustration for 'lonely' depicted a young person sitting alone, detached from a group of other young people. There is a subtle difference between being observed to be physically alone and feeling lonely or the emotion associated with being lonely, and one does not necessarily infer the other. The task was intended to

measure the emotion lonely, but it could be that participants' responses represented their belief that others with Down syndrome were more likely to spend time alone and not necessarily that they felt lonely. Similarly, when participants indicated whether 'lonely' or 'has lots of friends' applied to themselves it may be that their selection of 'lonely' meant they spent much time alone but not necessarily that they felt lonely. In addition, the inverse may also be true, that is, they may have selected the 'has lots of friends' picture simply because they had people around them a lot of the time, even if they did in fact feel lonely. Thus, it is important to acknowledge the challenges associated with measuring such precise constructs of human experience. The complexity involved in this endeavour may have been further exacerbated by choosing to represent such constructs pictorially. However, it is also noted that this potential limitation may have been tempered by the fact that the content of the images was guided by comments made by young people during a focus group discussion about the meaning of such constructs and careful piloting was carried out.

In retrospect, it was noted that some of the illustrations may have been a bit 'busy' and hence could have been improved if there had been less background detail. The illustration representing 'naughty' in the adjective task is an example, being probably the busiest of the pictures. Less detail in this illustration may have made it more readily comprehensible. However, that said, children's understanding of the illustrations did not emerge as a problem during data collection. In addition, piloting with the illustrations had been successful. In addition, as was noted during the piloting of the materials, the fact that the illustrations were presented in pairs in the Adjective task aided the comprehension of the illustrations and helped prevent possible confusion due to a small number of illustrations being 'busy' or having too much detail. There is also evidence suggesting that if illustrations are over simplified then they can be more difficult for individuals with intellectual disabilities to interpret. Matheson and Jahoda (2005) found that increasing contextual detail aided the recognition of emotional cues.

A criticism that may be levelled at the tasks is their transparency with regards what they were used to investigate. This may have led some participants to adjust their responses to what they thought the researcher wanted or expected. This may have been especially the case for the older non-disabled group, who may have inhibited their real views in order to be more socially desirable. On the other hand, the fact that the older non-disabled children provided more socially desirable responses perhaps reveals, in a different way, their



awareness that children with Down syndrome are part of a stigmatised group and that to openly express prejudicial views is socially unacceptable (Antonak and Livneh, 2000). One particular task, the Preference task, could be criticised for being a forced choice measure. The fact that this was a forced choice measure means that, while participants showed a preference to share activities with photographed others with no disability over those with Down syndrome, one does not know the extent to which the photographs of others with no disability were preferred. In other words, as a result of the forced choice nature of this task, the intensity of children's preference is not known. In addition, forced choice tasks confound preference of one photograph with rejection of the other. It is uncertain from the results of such measures whether it is preference for one photograph or avoidance of the other that is driving the response (Cameron et al., 2001).

The Sorting task may have been improved if more photographs were included for participants to sort. A greater number of photographs would have enabled the researcher to be more confident in participants' propensity to sort according to Down syndrome above chance level. However, collecting photographs presented such a challenge that this was just not possible in the present research.

### **7.4.2 Sample size**

A weakness of the study was the small sample of children with Down syndrome. The small sample was due to major difficulties recruiting participants with Down syndrome for the study. Recruitment was primarily through schools. Since the target sample was children with Down syndrome, in any one school there were only a handful of potential participants. Scarcity, combined with the low rate of consent forms being returned to the school from parents, resulted in only a few participants at most being recruited from one school. The participants who did take part came from twelve schools on the West coast of Scotland; in total 16 schools were involved but four schools reported that no consent forms had been returned.

A larger sample would have been preferable and would have allowed firmer conclusions to be drawn from the research. The schools who took part were incredibly helpful but recruiting participants through schools is a lengthy process. Permission is first required from the local authority to approach schools. In some cases it took months for the proposal to be approved. Once the go-ahead was obtained, liaising with schools was complicated

further by the difficulty of reaching busy head-teachers by telephone. Even when the schools were supportive, most study information sheets either did not make it home to families or did not make it back from the family home. A more efficient way of inviting families to take part in research may be through direct contact with them. One way of making this possible would be if researchers were able to pool the contact details of families who have expressed a willingness to take part in research. If potential participants gave their permission for their details to be held, then a database could be established that would contain contact details of families willing to be contacted about research.

### **7.4.3 Developmental differences across age groups**

A difference in task responses was not found between younger and older age groups. In retrospect it is believed this may have been a flaw in the design of the study. The age ranges of children in the two age groups were perhaps too close together to enable step-changes in development to be detected. Individual differences among the participants in each group may have washed out these developmentally significant changes. In other words, if the groups had been further apart in chronological age then developmentally significant differences between participants in each group would have been larger, and less likely to be washed out by smaller individual differences among group members.

### **7.4.4 Lack of control for developmental level**

A weakness of the study was that developmental level was not controlled for. Although this was factored into the design of the study, it proved impossible to do due to two unforeseen circumstances. The aim was to match participants with Down syndrome to participants without Down syndrome, according to level of verbal understanding, using BPVS-II scores. However, the BPVS-II scores of younger and older participants with Down syndrome over-lapped significantly, so much so that it was not possible to attain two distinct developmental-level age groups of participants with Down syndrome. In addition, when the BPVS-II scores were examined for participants with and without Down syndrome, it was found that participants with Down syndrome scored consistently lower than those without Down syndrome, and there was little overlap between the scores in the two groups. Therefore, it was impossible to control for developmental level within the present sample. It may have been possible to control for developmental level (using BPVS-II scores) if we had targeted participants further apart in age to form the age groups, for example, making the younger group 6 years to 11 years old and the older group 14 years

to 18 years old. Nevertheless, recruitment of these groups of children would still be a difficult task as the number of children with Down syndrome is limited in the first place. There were fewer children in schools on the West coast of Scotland than had been envisaged at the outset. A research database covering larger geographical area would be useful to researchers willing to travel further afield to increase participant numbers and achieve representative samples with greater variability among participants on a number of characteristics. This approach might allow the effects of different factors, including developmental level, to be examined.

The inability to match participants with Down syndrome to participants with no disability on BPVS-II was also perhaps a consequence of recruiting a large number of non-disabled participants from a mainstream school in an affluent area. The vocabulary of participants in this school may have been high for their age group. It is likely that this may have exacerbated the difficulty of matching children with and without an intellectual disability on a measure such as the BPVS-II. This factor may have been avoided but unfortunately was not foreseen.

## **7.5 Ethics in practice**

The awareness children and young people with Down syndrome have of their disability and the negative views in society that surround it are very sensitive issues, for both young people themselves and their families. As a consequence, researching this issue carried a number of important ethical considerations that had to be dealt with during the formulation of the project. In addition, there was an ethical dilemma that arose while the project was being carried out. These points will now be briefly described and discussed.

When thinking about how to research young people's awareness of Down syndrome it was of central concern that the project did not trigger awareness where there previously was none. Therefore, it was important that the method would not require the use of any terms related to the topic, such as, 'Down syndrome', 'disability' or 'difference'. In the parent information sheets, families were assured that such terms would never be used with the young people during the study, and that the researcher would be very careful and sensitive in her interactions with their children. Where recruitment took place with the help of schools, parent information sheets were sent home to children's families in sealed envelopes.

In the adjective task, young people were asked whether they thought that other children with Down syndrome, other children with no disability and themselves were likely to experience name-calling. This item was clearly a sensitive one and carried the potential ethical issue that young people would be upset as they had experienced bullying. One young person with Down syndrome did disclose that they had been bullied during this activity. However, he/she disclosed this in a very 'matter of fact' way and the researcher was careful to respond in a similar way, so as not to contribute to the distress the event may have already caused this young person. The school teacher who had arranged the researcher's visit was then informed.

There were also several ethical issues that arose in the process of carrying out the project. Field notes were taken about these instances as they arose and will be summarised here. In the initial phases of recruitment and piloting the researcher met with the deputy and head teacher of one school to discuss the project. During this discussion it became clear that the project and, in particular, the way the information sheets were written hit a raw nerve with teachers. They were uncomfortable with the singling out of children with Down syndrome as a group for the research and in particular the repeated use of the terms 'with Down syndrome'/ 'without Down syndrome' in the information sheets. They explained that this ran counter to their school ethos, that children should not be labelled in terms of their particular disability. Instead, differences among children were talked about in terms of individual strengths and educational needs. However, during further discussion, teachers were assured that the aim of the project was not to label or single out this group of children, in terms of them being 'different' from children with other disabilities, or indeed from children with no apparent disabilities. Instead the aim was to investigate this group of children's potentially unique experiences of themselves in society, and ultimately to help ensure they develop a positive self-identity. In addition, teachers were reassured that it was hoped the study would lead to further research with young people with intellectual disabilities more generally, to explore their experience as well. The information sheets were also re-written to be more sensitive to the teachers concerns.

While carrying out the research the researcher also faced an ethical dilemma when she met with children in the family home, as many of the parents wished to be present when their children completed the tasks. This may, in part, have been to ensure their child's safety. Yet it became very apparent that the overriding reason they wanted to be present was to see how their child responded. This is perhaps testament to the fact that families felt uncertain of their child's awareness of their Down syndrome and considered it very important.

If the parent was agreeable, it was of course ideal if they allowed the researcher to meet with the child by themselves. This ensured confidentiality for the child and helped to ensure that their responses were not influenced by their parent being present. However, there were many parents who did wish to be there and it was the family home. Consequently, the researcher decided that parents could be present as long as their child was happy with this. The parents were asked to remain a distance away and not to speak during the procedure.

While the precautions outlined above were put in place for the children, it was a parent's reaction during an interview at a family home that highlighted an unexpected ethical issue. The family were interested and concerned about their child's awareness of Down syndrome and were very keen to sit in on their child's participation in the project. During the tasks, the child behaved in a particularly disparaging way towards the photographs of young people with Down syndrome and intermittently exclaimed 'yuck' at these photographs. The parent became distressed seeing this behaviour from her child. The researcher handled this very sensitive situation with care and took several courses of action. The first was to recognise that the parent was upset by what she had seen, and it was also explained that the tasks were in not like formal assessments used by a professional. When talking with the parent it became apparent that as a family they were well supported and were already in contact with organisations that provide support to families with children who have disabilities. Despite being upset by the results, the parent was very positive about the aims of research itself and was thankful that her daughter had taken part.

In carrying out this research it became clear that while it was important to be mindful of the many ethical issues that could potentially arise, there are also often issues that are unforeseen. Therefore, it was crucial that the researcher remained alive to ethical issues throughout the research process and was prepared to deal with such instances sensitively.

## **7.6 Implications for policy and practice**

### **7.6.1 Need for early promotion of positive attitudes towards disability**

It appears then that many children with Down syndrome do have at least some awareness of Down syndrome from a young age. However, the findings also suggest that this is rarely

a subject that is directly broached with them. If this is the case then it might be appropriate to promote a positive understanding of Down syndrome at a relatively young age, to counteract the negative perceptions that these children seem to develop. One approach would be to encourage children to acknowledge and celebrate difference. After all, the stigma associated with Down syndrome and intellectual disability may be exacerbated or fuelled by children's perceptions of it being a taboo subject and a difference that is not talked about. In other words, ignoring this sensitive issue that children are evidently aware of may be harmful. Finding out what young people with Down syndrome think in the first place might also be helpful and the approaches taken in the present study may be of practical use as a starting point in this regard.

### **7.6.2 Future uses of materials**

The materials used in the present study appear to have been successful in allowing children as young as 8 years old with Down syndrome to indicate their awareness and feelings towards Down syndrome. The children therefore used the materials to communicate emotive views and appeared to find the sessions engaging and enjoyable, suggesting that the approach could be used in clinical or educational settings, to explore the children's awareness of and views about disability.

The type of materials used in the study might also be even prove helpful in a family context. The mothers who were interviewed all said that they found it distressing to think about whether or not their child was aware of Down syndrome. This anxiety largely stemmed from uncertainty regarding their child's awareness and uncertainty about what was the 'right thing to do'. A default position appeared to be to wait for the child to ask questions or request information about Down syndrome. In contrast to the parents of intellectually disabled adults interviewed by Todd and Shearn (1997), at no point was there a suggestion that mothers made a deliberate attempt to hide information about Down syndrome from their children. If mothers had thought their child was aware of Down syndrome they recognised that it was an issue that their child would need support with. Therefore, the methods used in the present study could help families to explore their child's awareness of their disability. This could alleviate some of the uncertainty and anxiety surrounding the issue, empowering families to then seek support about how to discuss disability with their child or give them confidence to do so on their own. A particular strength of the materials used in the study is that they do not assume understanding on the

part of the child. This is likely to be important to parents, who may be deeply worried about bringing up the subject of Down syndrome too soon. Part of the dilemma for parents is that to find out if their child is aware of Down syndrome parents have to ask, thereby running the risk of making them aware of Down syndrome before they were ready. Therefore, using materials similar to those in the present study parents may be able to obtain the information they need to make a decision regarding broaching the issue of disability with their child, without having to disclose it to them to find out. Clearly adaptations would be required to make the materials more suitable for use by families.

### **7.6.3 Promoting social inclusion?**

While the social inclusion of children with disabilities in mainstream education is central in social policy and legislation (for example, the Standards in Scotland's Schools etc Act, 2000), the findings of the present study suggest that further work is needed to ensure that children are fully included it would appear it has a long way to go before children are actually included. The mothers that took part in the present investigation often felt their children were not experiencing the socially inclusion it was hoped they would enjoy in mainstream school. It appeared that social distance experienced by children with Down syndrome from their mainstream school peers was, at least in part, the result of limitations in shared interests and communication difficulties, particularly in the later years of primary school. These findings raise the question as to what could be done to promote greater social inclusion for children?

Mothers expressed the view that special education environment holds social benefits for children with intellectual disabilities. Special school appeared to provide children with peers with whom they are able to socialise with more fully. In addition, it could be argued that special schools afforded pupils with opportunities for more positive social comparisons at an academic level. It seems then that it is important for children to come into contact with a range of peers, some of whom have difficulties like theirs. However, this does not appear to be the case in inclusion in mainstream schools. Instead, the common pattern seems to be one child with an intellectual disability in a school of mainstream peers. Perhaps the model whereby special education facilities and mainstream schools share the same campus provides the best of both worlds, providing that efforts are made to promote opportunities for the children to mix and socialise. More thought is required to find ways of helping children of different abilities to share common ground and

enable genuine relationships to flourish. Mainstream schooling or promoting integration on a shared campus is not just about opportunities for the children with Down syndrome, it is also about promoting more positive attitudes amongst the non-disabled children.

The findings from the non-disabled children add to the small previous literature by highlighting that young children are sensitive to differences in their peers and often hold negative views. It should be noted that many of the youngsters that took part in this study were known to have had varying degrees of awareness of Down syndrome and contact with at least one peer with Down syndrome. Perhaps instead of waiting for children demonstrate their awareness of disability, a more direct approach is required by schools to point out and celebrate difference. After all, it may be that young children interpret the absence of information or conversation about disability as a sign of the devalued status of their peers with a disability. In turn, this may beg the question, why ignore something that is obvious to the children?

## **7.7..Future research**

The future use of the tasks in research or clinical settings depends on them being demonstrated to be valid and reliable measures. Unfortunately, the timescale for this PhD meant that collecting psychometric data on the tasks was not possible. Therefore, a priority for future research would be to investigate the test-retest reliability of the tasks, their internal consistency and whether they are valid measures of the constructs they have been designed to examine.

This was the first study to examine children with Down syndrome's awareness of their disability from the age of eight years old. However, it remains unclear when and how early this awareness of difference and seemingly negative views towards Down syndrome emerge. Future research could build on the present work by including younger children. The methods may need to be adapted but the Preference task in the present study appeared to work particularly well and may be suitable in its current form for use with younger children.

The present research offers a snapshot of children's awareness at one point in time. It would be worthwhile to carry out a longitudinal study to investigate how children's views of Down syndrome change as they grow older and make the transition towards adulthood.



There is no research and little theorising about what it is like to grow up as a stigmatised individual with Down syndrome or an intellectual disability more generally. It would be interesting to examine whether individuals' attitudes to other people with Down syndrome become more positive as they grow older and realise that they cannot avoid being identified as having Down syndrome by others. More generally, it would seem important to examine how the relationship between individuals' perceptions of self and others may have longer-term implications for their emotional well-being. For example, the present research raises the question of whether a disparity between the negative perceptions of others with Down syndrome and positive views of self can be upheld in the long term. It is particularly important to begin to research developmental factors that help to promote children's resilience and a positive sense of self in the face of stigma.

The qualitative findings with the mothers also open up a number of important areas of research. How mothers manage their feelings about their child's stigmatised identity may be important to examine, since this aspect of their child's social identity appeared to present a personal struggle for them to come to terms with also. Mothers' anxiety about disclosing information about Down syndrome to their children stemmed from how much they felt the stigma attached to it and a strong desire to protect their child. The mothers then were required to reconcile how they saw their child, which was obviously as any other mother views their child and unrelated to Down syndrome, and their child's socially ascribed identity. That their child was the target of a prescribed social identity seemed to be a bigger issue for some mothers more than others, but may be an area where support is required. The interviews with mothers also suggested that families generally put a lot of weight on verbal forms of communication and perhaps there is a place for helping families to be more aware of other non-verbal forms of communication.

The present study focussed on people with Down syndrome. However, it is also important to extend the present research to children with intellectual disability more generally. This presents a methodological challenge since many people with intellectual disabilities do not have distinctive physical features that make them identifiable from photographs. However, perhaps methods taking advantage of other audio-visual techniques, such as video, may be useful here. Video may be used as it would portray more subtle cues indicative of intellectual disability, such as vocal differences or a distinctive gait. It would be interesting to find out when children notice such behavioural differences in others and what feelings they hold about them at an early age and as they grow older.

The development of ways to investigate the self-understanding of people who have difficulties with verbal expression is a methodological challenge. In addition the present research indicates that it is not just novel methods of investigation that may need to be created but also more diverse ways of thinking about self-understanding that do not depend on verbal means of doing so. Developmental research has tended to focus on aspects of self that are expressed verbally (Harter, 1999). However, the developmental literature also highlights that before children's verbal abilities develop they have quite a sophisticated knowledge of themselves (Rochat, 2001). Perhaps future research could draw on this literature and try to widen our scope when thinking about and researching self-understanding, so that we are not confined to verbal expressions of self.

Developmental psychological methods were used in the present research. This was a fruitful avenue that could be explored further. Thus, in addition to providing a useful theoretical base that could be explored to understand conceptions of self, developmental psychology could be further capitalised on in terms of methods.

The significance of research such as the present lies in its implications for real life. Therefore, an important avenue for future research is to investigate the relationships between the views that children indicate in experimental tasks and their actual real life behaviours towards others with disabilities. Firstly, it would be interesting to consider whether children with Down syndrome's views as expressed during tasks relate to the behaviours they show towards their peers with Down syndrome. It is known that many were friends with others with Down syndrome in their class. Therefore, the question arises, why did they express negative views about photographs of unfamiliar children with Down syndrome? Perhaps the photographs represented exemplars of the social category whereas children's real life peers were quickly assimilated on a more personal level. Or perhaps children were influenced by their ideas of what they thought the researcher expected them to say. Future research could explore these possibilities. For children without Down syndrome, again it would be important to consider if their views match their real-life behaviours. Many of the older participants indicated a greater receptiveness to sharing activities with photographed children with Down syndrome. It would be interesting to see if this translated into real life behaviour. Observational research in schools is therefore needed to help tease out the factors that contribute towards children's expressed views and whether or not they enact them in real life.

As was indicated earlier, future research would benefit from a database of potential participants, so that they may contact them directly. This would not only ensure that families received their invitation (as it is believed many information sheets never made it to the family home, instead being lost in transit) but also make the process of making contact with families considerably faster. On a side note, many mothers indicated they were keen to be involved in research, as they viewed their involvement as contributing towards something that could potentially improve the quality of life of people with Down syndrome.

In addition, such a database may be useful for collecting the materials required to carry out research. As already discussed, the collection of photographs for the present study was a very long and arduous task. Such a database would have helped to make the collection of photographs speedier.

## Chapter 8: Conclusions

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The present thesis has attempted to explore the understanding and feelings that children with Down syndrome have towards their disability and themselves. It has indicated that in contrast to what families often believe children may have a rudimentary awareness of Down syndrome and of the social stigma attached to it. This finding underscores the importance of giving children a voice. It also highlights that it may be important to consider how to aid children's understanding of Down syndrome early on and support them to think about it in a positive light, alongside ways to deal with the social stigma that exists. Further developmental work into children's emerging understanding will also help to inform this. It is also important to remember that although children seemed to be aware that Down syndrome had a negative social value, they were on the whole positive about themselves. Thus, perhaps talking to children about their Down syndrome earlier would harness their positive outlook and help to ensure it prevails.

Children's social experiences may be an important source of their feelings of difference. The concerns expressed by mothers' about their children's increasing social distance from mainstream school peers are important reminders that feelings of difference may stem from subtle features of their interactions with peers, not necessarily outright stigmatisation. Do children feel like an unequal communication partner when socialising with non-disabled peers? Several of the behaviours that mothers reported suggest that they do. The first was seeking the company of younger non-disabled children. The second was seeking out interactions with adults, who perhaps are more supportive of children's communication needs than children their age could be. Inclusion did not appear to be a reality for the participants with Down syndrome in this study. It would seem that there is a need for interventions in schools to help children relate to each other better. Helping children understand each other's communication needs would benefit all children.

For mothers, the fact that society considered their child as 'different' seemed to represent a personal struggle. Their own knowledge of the stigma associated with Down syndrome drove them to protect their child from it.

This thesis has focussed on children with Down syndrome. 'Down syndrome' is a condition that arises as a result of a chromosomal disorder and is viewed by some in medical terms. In the research world too, people with Down syndrome tend to be treated as a group of people who share the same condition. The down side of such group treatment is when it

becomes associated with a negative stereotype, as in a social stigma. Common to all these perspectives is a neglect of the individual and it is easy to forget that children with Down syndrome grow up in unique families and emerge as unique individuals. It is also important to remember that intellectually disabled or not, people show remarkable resilience in the way they cope with challenges in their lives and can continue to lead meaningful lives and fulfil roles as siblings, children and grandchildren in families who love them.

That intellectual disability has real effects on people's lives is clear, but there is more to people than the intellectual challenges and stigma that they and their families may face. It is the unique bonds and relationships that people develop with one another that help to determine how they perceive themselves and how they are viewed by others. This was captured in a moving letter written by a lady to her late sister, who had Down syndrome, recently published in the Guardian newspaper. The anonymous correspondent writes of her first awareness of her sister's difference:

*'I never knew you had Down's syndrome until I was about seven, when school friends pointed out that you were different. You were a force of nature and things made sense in your world.'*

There was the clear sense from the correspondent that she was a sister first and that her identity as someone with Down syndrome emerged later. As they grew older they remained close, but their paths diverged, heightening a sense of difference.

*'We were like any other sisters really, pulling and pinching at one another at one moment, kissing and cuddling the next. When I started to grow into a young woman our mother compared the Christmas gifts we were given by others. I was given makeup and clothes and you got colouring or art activities – something you loved. I suppose for our mum it was the realisation you would be staying and I would eventually be going, which I found hard to understand at the time.'*

*As I hit adolescence, I remember the focus of our mum's attention on you. I think she found it painful to think of me growing and leaving as it reminded her of the unfolding destiny ahead: not only as a mother but as a full-time carer for the rest of your life.'*

*You and Mum watched me move far away, get a degree and become a teacher. Then I became a wife and mother.'*

This thesis suggests that for many children with Down syndrome there also may be an unspoken awareness, not only of difference, but of shared family bonds and social experience. Perhaps much remains unsaid due to the underlying emotion, captured by the correspondent above, or because much of what defines children and those closest to them relates to everyday experiences and events. Perhaps, rather than always separating out aspects of identity, including those related to stigma, research concerning people with Down syndrome and other individuals with an intellectual disability should also seek to examine how individuals negotiate their identities in their everyday lives and relationships.

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## Appendices

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Appendix A: Letter of ethical approval from University of Glasgow Ethics Committee

Appendix B: Participant information sheet for families with a child with Down syndrome

Appendix C: Participant information sheet for families with a child with no disability

Appendix D: Young persons' consent form for participants with no disability

Appendix E: Young persons' consent form for participants with Down syndrome

Appendix F: Caregiver Interview Schedule

Appendix G: Samples of mothers' interview transcripts with analysis

## Appendix A: Letter of ethical approval from University of Glasgow Ethics Committee



Ms Karen Deakin  
Academic Unit for Mental Health and Well Being  
Admin Building  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow, G12 0XH

21 February 2011

Dear Ms Deakin

**Medical Faculty Ethics Committee**

**Project Title: Children's perceptions of Down's Syndrome**

**Project No.: FM03510**

The Faculty Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study now that the requested revisions have been incorporated. They are happy therefore to approve the project, subject to the following conditions:

- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- If the study does not start within three years of the date of this letter, the project should be resubmitted.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

A handwritten signature in black ink, appearing to read 'D. Shaw'.

Dr David Shaw  
Faculty Ethics Officer

**Dr D Shaw**  
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## Appendix B: Participant information sheet for families with a child with Down syndrome



Dear Parent/ Carer

### Invitation to take part in a research project

Hello, my name is Karen Deakin and I am a postgraduate student at the University of Glasgow. My supervisor is Professor Andrew Jahoda, a Psychologist who works at the University.

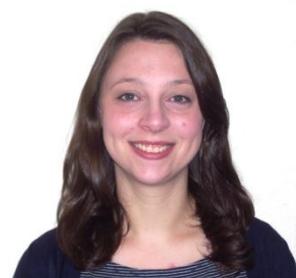
I would like to invite you and your child to take part in research I am carrying out as part of my PhD. The aim of the research is to find out how children with Down's syndrome see themselves and what their views are of other children. To find out what children think, in a way that is fun, I will visit to play some picture games with them. I would also really like to speak with carers of children with Down's syndrome, to find out what they think about their child's developing identity. So, I ask if you would like to take part in an interview, at a time and place that is convenient for you. If you are happy for your child to take part, but do not wish to be interviewed yourself, that is also okay.

I have written an information sheet to tell you more about the project and to help you decide whether or not you wish to take part, and whether you wish to allow your child to take part. I have attached it to this letter. I hope you will have time to read the information sheet and discuss it with others if you wish. If you have any questions about the project, please do not hesitate to get in touch (my contact details are below).

Thank you for taking the time to read this. I look forward to hearing from you.

Kind regards

Karen Deakin



### Mental Health & Wellbeing

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## Investigating children with Down syndrome's views about themselves and others

### What does this project aim to find out?

It is important for children to develop a positive view of themselves. The aim of this project is to find out how children see themselves and others. To find out what children think, in a way that is fun, the researcher will play some picture matching activities with them.

Also as part of this project, the researcher would like to speak with the caregiver's of children to find out what they think about their child's developing identity.

### What will happen if my child and I decide to take part?

If you would like your child to take part, please return the attached consent form using the stamped addressed envelope provided. The researcher will then call you to answer any questions you might have and to arrange a time that suits you for her to visit your child.

When the researcher visits your home, your child will be asked if they would like to help the researcher by looking at some pictures with her. In the activities, your child will look at photos and pictures of lots of boys and girls, some of whom have Down syndrome and others who do not. Some example pictures and photos are shown below.



©Richard Bailey

In one activity, your child will be asked to choose from the photos who they would most like to spend time with. In another, your child will be asked to describe the children in photos by matching them to pictures. Lastly, he or she will be asked to match some pictures to words. The researcher will also take a portrait photo of your child to use in the activities. This will be torn up when the activity is finished.

The researcher recognises that this is a sensitive topic and she will be very careful not to influence children in any way.

If you would like to take part in an interview with the researcher, please also return the second consent form. The researcher will then also call to arrange a time that is convenient for you to speak with her.

If you would like your child to take part, but do not wish to be interviewed, that is okay too.

### Why have my child and I been chosen?

The researcher contacted the head teachers of schools who have pupils with learning needs, organisations who are involved in providing support to children and their families, and clubs that young people attend. These people have kindly agreed to pass this information on to you. The researcher hopes to talk to 32 children aged between 10 and 17 years and one of their caregivers.

### Does my child or I have to take part?

No. It is entirely up to you to decide whether or not you wish to allow your child to take part, and whether or not you also take part.

If you decide to allow your child to take part, please sign and return the attached consent form on your child's behalf. Your child will be asked by the researcher whether or not they wish to take part. If they would like to take part, it will be explained to them that it is okay if they want to withdraw from the project at any time without giving a reason. Similarly, even if you have given your consent, you are able to withdraw your child from the study at any time without giving a reason.

If you also decide to take part, please sign and return the caregiver consent form. You may withdraw from the study at any time without giving a reason. You will be given this information sheet to keep and a copy of both consent forms.

### Confidentiality

All of the information collected during the project will be kept strictly confidential; any information about you will have your name removed so that you cannot be recognised.

### Who has reviewed the study?

The project has been reviewed by the Faculty of Medicine Ethics Committee. The researcher also holds a current Enhanced Disclosure Scotland certificate.

### What will happen to the results of the research study?

It is hoped that the information gathered during this study will be useful in helping us understand what children think about themselves and others. This information should be helpful in providing families and schools with ideas about how to foster positive identities. The research findings will also be written into reports, which may be published. It will not be possible to identify any of the individuals who take part in this study from the reports, as all information will be made anonymous. All those who take part in the study will be sent a summary of the findings.

**Thank you so much for your time**

**If you have any questions at all, please do not hesitate to get in touch**

Karen Deakin  
University of Glasgow  
Mental Health & Wellbeing  
Tel: 0141 211 3904  
Email: k.deakin.1@research.gla.ac.uk





University  
of Glasgow

## Consent form

(For your child to take part)

Investigating children with Down syndrome's views about themselves and others

Name of research student: Karen Deakin

Supervised by: Andrew Jahoda

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand my child's participation is voluntary and that my child is able to withdraw, and I am able to withdraw my child, from the project at any time without giving any reason, without my legal rights being affected.
3. I agree for my child to take part in the above study.
4. I give my permission for my child's photograph to taken (this will be torn up immediately after use).

\_\_\_\_\_  
Name of child

\_\_\_\_\_  
Date

\_\_\_\_\_  
Carer signature

\_\_\_\_\_  
Child's Date of Birth

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Please provide a telephone number or e-mail address below, for the researcher to contact you.

Telephone number:

E-mail:

If you would like to take part in an interview with the researcher, please also complete and return the consent form overleaf.



Consent form

(To take part in an interview)

Investigating children with Down syndrome's views about themselves and others

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand my participation is voluntary and that I am able to withdraw from the project at any time without giving any reason, without my legal rights being affected.

3. I agree to take part in the above study.

\_\_\_\_\_

Name of participant

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Researcher

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

Please provide a contact telephone number or e-mail address below, for the researcher to contact you.

Telephone number:

E-mail:

## Appendix C: Participant information sheet for families with child with no disability



Dear Parent/ Carer

### Invitation to take part in a research project

My name is Karen Deakin and I am a postgraduate student at the University of Glasgow. My supervisor is Professor Andrew Jahoda, a Psychologist who works at the University.

For my PhD I am carrying out a research project looking at children and young people's awareness and ideas about Down's syndrome. To find out what they think, in a way that they will find fun, I will ask them to play some picture matching activities with me.

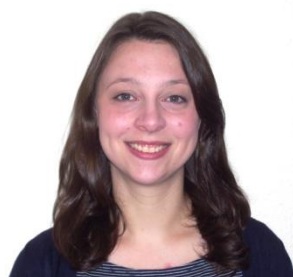
I would like to invite your child to take part in this project. I have written an information sheet to tell you more about it and to help you decide whether you wish to allow your child to take part. I have attached it to this letter. I hope you will have time to read the information sheet and discuss it with others if you wish. If you have any questions at all about the project, please do not hesitate to get in touch (my contact details are below).

Thank you for taking the time to read this. I look forward to hearing from you.

Kind regards

Karen Deakin

A handwritten signature in black ink that reads 'K Deakin'.



### Mental Health & Wellbeing

Gartnavel Royal Hospital  
2<sup>nd</sup> Floor, Admin. Building  
1055 Great Western Road  
Glasgow G12 0XH  
Tel: 0141 211 3904  
Email: k.deakin.1@research.gla.ac.uk

The University of Glasgow, charity number SC004401



## Investigating children and young people's perceptions of others

### What does this project aim to find out?

The aim of this project is to find out about children and young people's awareness of Down's syndrome and what views, if any, they hold about it. The researcher also wishes to discover how salient Down's syndrome is to them, so, it is important that their attention is not drawn to what the project is about before they have taken part. To find out what children and young people think, the researcher will invite them to do some activities that involve looking at photographs and pictures of many different people their age.

### What will happen if I decide to allow my child to take part?

If you would like your child to take part, please return the attached consent form to your child's school. If you like, you can also provide a telephone number and the researcher will call you at home to introduce herself and answer any questions you have about the project.

The researcher will then visit your child at their school. She will ask your child if they would like to help her with some picture activities. During these activities your child will look at photos and pictures of many boys and girls. Some of the photos will show children with Down's syndrome.

In one activity, your child will be asked to choose from the photos who they would like to spend time with. In another, your child will be asked to describe the children in photos by matching them to pictures. Lastly, he or she will be asked to match some pictures to words. The researcher will also take a portrait photo of your child to use in the activities. This will be torn up when the activity is finished. However, if you are willing to allow your child's photo to be used in future research with other children you can give permission for this on the consent form.

It is recognised that this is a sensitive topic. The researcher will be very careful not to influence children or to highlight any differences between children.

### Why has my child been chosen?

The researcher hopes to talk to 64 children aged between 6 and 16 years.

### Does my child have to take part?

No. It is entirely up to you to decide whether you wish to allow your child to take part.

If you decide to allow your child to take part, I would be grateful if you could sign the attached consent form on their behalf, and return this to your child's school. Your child will be asked by the researcher whether or not they wish to take part. If they would like to take part, it will be explained that it is okay if they want to withdraw from the project at any time without giving a reason. Similarly, even if you have given your consent, you are able to withdraw your child from the study at any time without giving a reason.

### Confidentiality

All of the information collected during the project will be kept strictly confidential and all information will have names removed from it, so that no child may be recognised.

### Who has reviewed the study?

The project has been reviewed by the Faculty of Medicine Ethics Committee. The researcher also holds a current Enhanced Disclosure Scotland certificate.

### What will happen to the results of the research study?

It is hoped that the information gathered during this study will be useful in helping us understand what children think about themselves and others. This information should be helpful in providing families and schools with ideas about how to foster positive identities. The research findings will also be written into reports, which may be published. It will not be possible to identify any of the individuals who take part in this study from the reports, as all information will be made anonymous. All those who take part in the study will be sent a summary of the findings.

Thank you for your time.

If you have any questions, please do not hesitate to get in touch.

Karen Deakin  
University of Glasgow  
Mental Health & Wellbeing

Tel: 0141 211 3904

Email: k.deakin.1@research.gla.ac.uk



### Consent Form

#### Investigating children and young people's perceptions of others

Name of research student: Karen Deakin

Supervised by: Andrew Jahoda

Please initial box

- 1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
  
- 2. I understand my child's participation is voluntary and that my child is able to withdraw, and I am able to withdraw my child, from the project at any time without giving any reason, without my legal rights being affected.
  
- 3. I agree for my child to take part in the above study.

\_\_\_\_\_

Name of child

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Child's Date of Birth

\_\_\_\_\_

Researcher

\_\_\_\_\_

Date

\_\_\_\_\_

Signature



## Consent Form

### Investigating children and young people's perceptions of others

Name of research student: Karen Deakin

Supervised by: Andrew Jahoda

Please initial box

- |  |   |
|--|---|
| 1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.  | <input style="width: 40px; height: 30px;" type="checkbox"/> |
| 2. I understand my child's participation is voluntary and that my child is able to withdraw, and I am able to withdraw my child, from the project at any time without giving any reason, without my legal rights being affected. | <input style="width: 40px; height: 30px;" type="checkbox"/> |
| 3. I agree for my child to take part in the above study.   | <input style="width: 40px; height: 30px;" type="checkbox"/> |
| 4. I give my permission for my child's photograph to be used in similar research by the same researcher (if you do not sign this box, I will destroy the photograph immediately after use).                                      | <input style="width: 40px; height: 30px;" type="checkbox"/> |

\_\_\_\_\_

Name of child

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Child's Date of Birth

\_\_\_\_\_

Researcher

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

## Appendix D: Young persons' consent form for participants with no disability



Dear Parent/ Carer

### Invitation to take part in a research project

My name is Karen Deakin and I am a postgraduate student at the University of Glasgow. My supervisor is Professor Andrew Jahoda, a Psychologist who works at the University.

For my PhD I am carrying out a research project looking at children and young people's awareness and ideas about Down's syndrome. To find out what they think, in a way that they will find fun, I will ask them to play some picture matching activities with me.

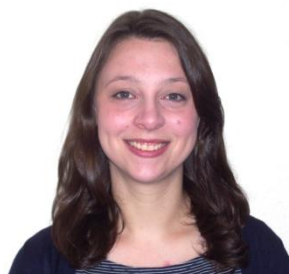
I would like to invite your child to take part in this project. I have written an information sheet to tell you more about it and to help you decide whether you wish to allow your child to take part. I have attached it to this letter. I hope you will have time to read the information sheet and discuss it with others if you wish. If you have any questions at all about the project, please do not hesitate to get in touch (my contact details are below).

Thank you for taking the time to read this. I look forward to hearing from you.

Kind regards

Karen Deakin

A handwritten signature in black ink that reads 'K Deakin'.



### Mental Health & Wellbeing

Gartnavel Royal Hospital  
2<sup>nd</sup> Floor, Admin. Building  
1055 Great Western Road  
Glasgow G12 0XH  
Tel: 0141 211 3904  
Email: k.deakin.1@research.gla.ac.uk





## Investigating children and young people's perceptions of others

### What does this project aim to find out?

The aim of this project is to find out about children and young people's awareness of Down's syndrome and what views, if any, they hold about it. The researcher also wishes to discover how salient Down's syndrome is to them, so, it is important that their attention is not drawn to what the project is about before they have taken part. To find out what children and young people think, the researcher will invite them to do some activities that involve looking at photographs and pictures of many different people their age.

### What will happen if I decide to allow my child to take part?

If you would like your child to take part, please return the attached consent form to your child's school. If you like, you can also provide a telephone number and the researcher will call you at home to introduce herself and answer any questions you have about the project.

The researcher will then visit your child at their school. She will ask your child if they would like to help her with some picture activities. During these activities your child will look at photos and pictures of many boys and girls. Some of the photos will show children with Down's syndrome.

In one activity, your child will be asked to choose from the photos who they would like to spend time with. In another, your child will be asked to describe the children in photos by matching them to pictures. Lastly, he or she will be asked to match some pictures to words. The researcher will also take a portrait photo of your child to use in the activities. This will be torn up when the activity is finished. However, if you are willing to allow your child's photo to be used in future research with other children you can give permission for this on the consent form.

It is recognised that this is a sensitive topic. The researcher will be very careful not to influence children or to highlight any differences between children.

### Why has my child been chosen?

The researcher hopes to talk to 64 children aged between 6 and 16 years.

### Does my child have to take part?

No. It is entirely up to you to decide whether you wish to allow your child to take part.

If you decide to allow your child to take part, I would be grateful if you could sign the attached consent form on their behalf, and return this to your child's school. Your child will be asked by the researcher whether or not they wish to take part. If they would like to take part, it will be explained that it is okay if they want to withdraw from the project at any time without giving a reason. Similarly, even if you have given your consent, you are able to withdraw your child from the study at any time without giving a reason.

### Confidentiality

All of the information collected during the project will be kept strictly confidential and all information will have names removed from it, so that no child may be recognised.

### Who has reviewed the study?

The project has been reviewed by the Faculty of Medicine Ethics Committee. The researcher also holds a current Enhanced Disclosure Scotland certificate.

### What will happen to the results of the research study?

It is hoped that the information gathered during this study will be useful in helping us understand what children think about themselves and others. This information should be helpful in providing families and schools with ideas about how to foster positive identities. The research findings will also be written into reports, which may be published. It will not be possible to identify any of the individuals who take part in this study from the reports, as all information will be made anonymous. All those who take part in the study will be sent a summary of the findings.

Thank you for your time.

If you have any questions, please do not hesitate to get in touch.

Karen Deakin  
University of Glasgow  
Mental Health & Wellbeing

Tel: 0141 211 3904

Email: k.deakin.1@research.gla.ac.uk



## Consent Form

### Investigating children and young people's perceptions of others

Name of research student: Karen Deakin

Supervised by: Andrew Jahoda

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
  
2. I understand my child's participation is voluntary and that my child is able to withdraw, and I am able to withdraw my child, from the project at any time without giving any reason, without my legal rights being affected.
  
3. I agree for my child to take part in the above study.
  
4. I give my permission for my child's photograph to be used in similar research by the same researcher (if you do not sign this box, I will destroy the photograph immediately after use).

\_\_\_\_\_

Name of child

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Child's Date of Birth

\_\_\_\_\_

Researcher

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

## Appendix E: Young persons' consent form for participants with Down syndrome

**Invitation to take part in a study**UNIVERSITY  
of  
GLASGOW

Hello my name is Karen Deakin.

I am asking if you would like to join in a study.

The study is to find out what you think about pictures of some children.

There are no right or wrong answers. I want to know what you think.

**Why are you asking me?**

I am asking you because you are aged between 10 and 17 years. I am speaking with other children your age as well.

**Did anyone check the research is okay to do?**

Yes. It was checked by a group of people called a Research Ethics Committee at the University of Glasgow. They made sure the research was fair.

**What will happen to me if I take part?**

I will ask you to look at some pictures and put them into boxes.

This will last a short time, 30 minutes.

**Do I have to take part?**

No. It is up to you.



If you would like to take part, I will ask you to sign a form. You can stop taking part at any time, without giving a reason. I will not talk about what you say to anyone else.

**Thank you for reading this****Consent Form**

Has somebody told you about this project? Yes/No

Do you know what the project is about Yes/No

Have you asked all the questions you want? Yes/No

Have your questions been answered? Yes/No

Do you know it's OK to stop taking part at any time? Yes/No

Are you happy to take part? Yes/No

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below.

Your name \_\_\_\_\_

Date \_\_\_\_\_

The researcher who explained this to you needs to sign too:

Name \_\_\_\_\_

Sign \_\_\_\_\_

Date \_\_\_\_\_

## Appendix E: Caregiver Interview Schedule

**Caregiver's perceptions concerning their child's awareness of disability and stigma**

**Thank you for agreeing to talk to me. If it's alright with you, what I'd like to do today is listen to your views about how (name child) sees him/herself compared with others.**

**1. Family context.**

If we would, I'd like to just start by finding out about your family, and who it's made up of.

- So, who are your family?
- Tell me a bit about your children?

**2. Views of self relative to siblings**

- How does (name child) get along with his brothers/sisters?
- How has their relationship changed as they've grown up?
- How do you think (name child) views him/herself in comparison with siblings?

**3. Views of special schooling**

- Where does (name child) go to school?
- How was his first day there? For you and child?
- Is that the same school as brothers/sisters?
- Did you decide on that school?
- Does (name child) ever ask questions about his/her school?
- How does (name child) feel about school?
- Where did (name child) go to primary school?
- How did (name child) find primary school?

**4. Views of self relative to peers**

- How does (name child) get on with other kids at school?
- Is there someone he/she spends a lot of time with?
- How does (name child) view himself compared with classmates?
- How aware is (name child) of different disabilities among his/her peers?
- How does he/she feel about people with disabilities?

## **5. Views of self concerning disability**

- Are there any incidents that come to mind when (name child) may have noticed DS/ disability?
- Does (name child) ever ask about anything to do with DS/disability?
- There are particular facial features associated with DS; had (name child) ever mentioned or asked about these?
- How does (name child) feel about it?

## **6. Parental practice**

- Have you found any differences in how you support (name child) compared to brothers/sisters?
- Have you ever thought about talking to (name child) about DS or disabilities?
- How do you feel it went?
- How did (name child) react?
- Have you thought about this?
- Discussed as a family?

## **7. Awareness of stigma**

- What kinds of things does (name child) enjoy doing outside the home?
- How does (name child) get on out and about?
- How do you find other people are with him/her?
- Do people stare or act funny around him/her?
- How does (name child) react to this?
- How do you feel when this happens?

## **8. Future self**

- How do you see the future?
- What hopes do you have for (name child)?
- How do you think (name child) may come to view him/herself in the future?
- How do you feel about that?
- How do you think you will cope with that?

## **9. Finishing off...**

- So, (name child) enjoys... How long has he/she liked that...?
- Thank you so much for speaking with me. Is there anything you'd like to add that I've not asked about? Anything important you think I've missed out?

- Sometimes I go away and realise I've forgotten to ask something, if this happens, would you mind if I gave you a wee call?

Demographics (do last): I also just have a few more quick questions about things that might affect your views. I'll just note your answers down here, if that's ok. Thanks.

Participant number: \_\_\_\_\_

Mother DoB: \_\_\_\_\_

Child DoB: \_\_\_\_\_

Highest Education Level: \_\_\_\_\_

Occupation: \_\_\_\_\_ (What kind of work have you done most of your life?)

Religion: \_\_\_\_\_

Postcode: \_\_\_\_\_

Family composition:

Family member	Age	Gender
1		
2		
3		
4		
5		
6		
7		



Appendix G: Samples of interview transcript from two mothers with analysis

<p>start with, and was actually sort of ahead of the class when she started, she could read when she went to school and things but aye over the years and things are starting to, the gaps are starting to widen with the other children. But we're very busy, they both like swimming, really keen swimmers, so we try and swim twice a week and Lydia dances, John plays ice hockey. Yes busy.</p>	<p>mainstream school started well but now gaps in ability appearing, distance. changes subject?</p>	<p>widening gap from mainstream peers.</p>
<p>ME: What is your husband's name sorry?</p>		
<p>MUM: Ewen.</p>		
<p>ME: And John and Lydia – how do they get along?</p>		
<p>MUM: Good, yep, most of the time like any other two. He's starting to, they both know, I told Lydia that she had Down's Syndrome, just like her cousin has asthma and I explained it a bit like that to her, I've got diabetes, just some people have got different things so we kind of explained it like that so John now knows that as well.</p>	<p>normal sibling relationship born later about DS, explained in terms of other individual differences</p>	<p>Disclosing DS explaining in terms of benign social differences</p>
<p>ME: When did you tell her that?</p>		
<p>MUM: I think I first introduced the word maybe about 2 or 3 years ago, she was about 7. Just... she doesn't, she still doesn't have a full understanding of it but she, I just brought the word, because I didn't want her to hear it and be like "No I don't. I don't know" so I introduced the kinda word and then a wee bit more and now she'll say, she knows herself, she'll say "Oh maths today but, because of this Down's Syndrome, it's tricky". And sometimes I don't know whether she's playing on it or not, but she'll say I need a little extra help or I need a wee bit longer, so she kind of knows but you've just got to watch she doesn't, like I say, play on it. And the two of them, he'll help her when he needs to but she kind of shows her authority over him because she's the older sometimes as well but, to be honest, they do get on quite well and they'll help each other when they can kinda thing. He's a lot more boisterous than she can be so em but yeah they do, they get on alright. They're good company, and they, in the holidays there, they wanted to go up to bed early to watch the DVD in the same room and they, they'll do things together, which is good.</p>	<p>introduced words when 7yo. advising explanation to feel of understanding getting in there first again - so didn't hear it elsewhere in less sensitive manner. explained in terms of DS, child aware of that + expressed in relevant terms. jeas plays on DS sibling relationship - negotiating roles around age and ability. positive relationships - doing activities together.</p>	<p>getting in there first, talking cannot/poking awareness of DS in terms of DS. negotiation of sibling relationship</p>
<p>ME: Do you think their relationship has changed as they've been getting older?</p>		
<p>MUM: He's probably better, he's slightly more understanding I would say, not understanding, but he kind of realises that she does need a wee bit extra time for things and things like that, em, I can see, he used to say "Oh, she's slow, I was quicker than her" but now he doesn't say that kind of thing cos he kinda knows, if they're running or playing about or whatever.</p>	<p>Sibling understanding of disability developing</p>	<p>Sibling understanding of disability</p>
<p>Me: Yeah</p>		
<p>Mum: So, just as he gets a wee bit older, he's realising as well, can see the differences, but aye no they get on alright.</p>		

<p>ME: And she goes to mainstream school?  Mum: yes  Me: And she's still at primary school then?  MUM: Yes, she's just went into primary 6.  ME: Does she like school?</p> <p>MUM: She loves school. She does, aye, she's always keen to go, we've never had a problem. Em, she's keen to learn as well. Em she's reading, her reading is really good but her comprehension's not so, not so good, she can read you a whole story and you think that was perfect but then if you ask her what it was about, it's a bit woolly. Em, aye no, she does, she loves school. The social side of things, as I said [before began recording, brought up herself], she struggles a bit. I'm saying that, she's happy in her own company em and she will go and play with others for a wee while but then she'll wonder away herself again just. Em, sometimes, I think it is if the conversation gets too much or the games get too much or whatever but em I'd say she's struggling a wee bit on that kind of side of things. She talks a better game about having a friend and doing things with a friend than she actually does. She's always wanting somebody to come over and if somebody comes over to play, she wants them to sit and watch her dance like we all have to do half the time but she thinks, she's not quite got that you have to kinda come and go and do what other people want sometimes. Em, just the kinda social side of things, as I say, I feel she struggles a wee bit.</p>	<p>enjoys school + learning  Social side of things prominent - brought up herself before interview even began.  struggles with social side of school - though doesn't bother her - chooses to play alone  complexity of conversation + games  talks about having friends and asks for friends over - "shows <del>it</del> minus friends desirable?"  Different expectations of friends</p>	<p>Mum's obs. of social difficulties  child - happy in own company.  complexity of mainstream peers interactions  Different ideas of friendship</p>
<p>ME: Do you think that she feels she struggles then?</p> <p>MUM: I don't think she feels it, I think she's quite happy. She doesn't, when she says "Oh I just wandered about myself at playtime" and I think "Oh God" and but she's happy. She's quite happy in her own company em or she can go to an adult, she'd rather go to an older child or an adult for company as to go to her own kind of peers. Because an older child or adult is more likely to do what she wants them to do and play along with her whereas other kids her age expect more of a kinda interaction I'd say.</p> <p>ME: OK, so she struggles a wee bit. How was her starting school for you?</p>	<p>child doesn't feel the struggle  older children/adults conform to expectations/needs friendship needs</p>	<p>happy in own company  different ideas/expectations of friends mismatch from peers.</p>
<p>MUM: Fine. What happened was she went into nursery just as soon as she turned 3 in the January but then they kept her in nursery for the full 2 1/2 years. She could've went, because her birthday was January, she could've went to school a year earlier than she is but we kept her behind to help her as best we could. Em, so, no, she went to school, she went to nursery which is next door to the school so Lydia' answer to going into Primary 1 was "I just go in another door now", that was, she didn't see the big deal, it was no big deal, we're greeting and everything and she just [laughs], no she was fine. Em, she doesn't have full time support or anything, she just em has an assistant, maybe for Maths time or Language time in the class, they come in for</p>	<p>transition to primary school from nursery environment for family, but unimportant to child</p>	

<p>whatever time, whether it's 30 minutes or whatever a day just to give her a wee hand and try and keep her on task at school. She's always had an assistant since she was wee. There was physiotherapist who came in, there was home school teacher who came in, so she's had a lot of one-to-one with adults as well, and it's trying to get the balance of people helping her but her not being dependent on them kind of thing, what we try to do.</p>	<p>a lot of support - wary about her getting too dependent on adults.</p>	
<p>ME: Is that the same school as John? MUM: Yeah, yep ME: So what primary is he in? MUM: He's Primary 3...it's just at the top of the road. She has walked a few times herself but em, but aye no, she's, I'm more wary than she is. But aye, no we're just at the top of the road, so we're not far to go.</p>		
<p>ME: So does she have any particular friends that she would spend time with?</p> <p>MUM: She has em my niece, who's the same age as John, they're quite close. They all play quite well together... em...the girls from the class...to be fair ..., no she doesn't have a particular friend, we did, she did have a very good wee friend, a wee girl who was in her class who was very, very good with her and they went to each other's houses and then she moved schools, em, but this wee girl, I really liked that wee girl, she was good with her but she didn't 'mummy' her, she would, they were trying to get off the stool one day and she was said to Lydia "right Lydia I'll show you how to get off it" and she encouraged her, but in a nice way, not over thingy way, she was an awful nice wee girl, and they still keep in touch but she's kind of went away in a different circle and I've, you have to try and keep contact but it's not really, it's not really happened. Em, she will go, if John is playing, she can kinda play, em he plays with a wee boy across the road and she can, she'll play with them sometimes if they're playing something she's interested in...em, but no she doesn't have a particular friend which kinda annoys me a wee bit but doesn't annoy her. Although she'll speak and say, there's things going on just now, she wants this wee girl from her class to come but she doesn't play with the wee girl in school so she keeps saying "can she come to my house", if you play with her in school, then you could ask her to come to the house, em but em I've tried to kinda bribe her with that, by saying if you play wi her in school I'll ask her to the house, but we'll see how that pans out, I'm not sure.</p>	<p>old friend - moved schools</p> <p>friend liked because didn't take away independence encouraged her and showed her how to do things - mummy viewed - well.</p> <p>tried to maintain contact, but not happened</p> <p>no particular friends now - upset mum but not her</p> <p>asks for friends over, but experience difficulties with these interactions at school. Mum confused?</p>	<p>friends moving on</p> <p>difficulty of maintaining friendships once <del>retained</del> moved on</p> <p>different idea of friendship?</p>
<p>ME: Has this situation changed do you think at all through primary school?</p> <p>MUM: No, it's always been like this. They've tried different things at school. As I say, this one wee girl I think she left in Primary 3, she was only in the first couple of years and she was good, but she's never really connected with one or other group. There only is 9 girls in the class and she can go and speak to any of them, she will kind of go in and out their groups at playtime and lunchtime and I</p>	<p>social difficulties issue near school is aware of / been involved in</p> <p>superficial relations w/ all girls - but no particular relationships / friends</p>	

<p>think she works OK in the class with them kinda thing but I try to encourage as well, she has a Facebook page and so does the class and I tried to encourage her over the holidays to contact them and send a wee message saying "Do you want to go swimming or something" and I could take them and that and she'd say "No I don't want to". So I won't say it's changed very much, it's always been a bit of an issue and sometimes we concentrate on it a lot and sometimes we just kind of let it go em and see how it goes but as I say she's not unhappy which is, if she was saying "Oh I don't have any friends to play with" then but it doesn't really worry her. So I think why should it worry me but I still try to encourage her and at the school tomorrow to encourage them to try and get her to mix a wee bit better, especially in a couple of years' time secondary coming up and I just think that's a bigger thing, it would be a comfort to me if I knew there was somebody kinda...</p>	<p>other times, reluctant to try to socialise          been a long term issue and worry for mum          reassured that child unaffected but still a worry unresolved          worry about what lack of friends might mean for future secondary school.</p>	<p>reluctant to socialise because difficult?          Social difficulties &amp; anxiety about future</p>
<p>ME: What are your thoughts on secondary school?</p> <p>MUM: I'm hoping that mainstream, she should be able to cope with mainstream. I would imagine she will need some sort of support but I'm hoping that...she's done so well kinda up to now that, I don't know, I feel we're at a kind of crossroads just now. She understands things she can see, things that are real, but imaginary things and things in her head are harder for her to perceive and some of the things they're doing, the topics are at school are the Victorian, Space and it's to decide, well does she really need to know all that? Or can we just concentrate on giving her extra time on the more important things? They say life skills, but I think, that annoys me because she's getting her life skills here, but things like technology and the computer and things like that, that'll help her more, to concentrate on things like that more than things that happened hundreds or thousands of years ago, you know, what does she understand so I'm kinda reading up on that myself just now to try and kinda see what is the best way to encourage her, try to keep her with a curriculum so hopefully she moves onto the secondary as best she can...we'll see. We've two years to worry about that...but I think I've got to start thinking about it and anything that needs to go in place so we've got plenty of time to, but she came in yesterday saying they got French so she was quite pleased about that. I think she will, she's quite good at that sort of thing, she remembers, I would say she has a kind of photographic memory. If she sees something written down and you tell her what it says once, she'll remember that.</p> <p>ME: I wish I could do that sometimes!</p> <p>MUM: So do I!</p>	<p>thinking about scheduling in terms of future needs and suitability of topics</p>	
<p>ME: So you were saying that you don't think she's bothered socially at school. Do you think she sees any difference between her and the other kids at school?</p> <p>MUM: Not in that kinda social typical environment but, as</p>		

<p>I say, she does mention and she knows that in PE and things "I couldn't do that because that's too tricky for me". She knows, but oh at sports day it was a surprise, she ended up winning this year because they did the sack race so Lydia just carried the sack and ran and she won so that was great! But the year before it was the three legged race and it just about broke your heart. She's got enough coordination just to get herself going never mind coordinating with somebody else! But she doesn't, like she wasn't embarrassed that she was running herself holding the sack and everyone else was in it, she didn't think "Oh that's not right" She said "I won" and I said "Aye right you did!", it's the first time she's done anything like that. So I don't know that...it doesn't bother her. She knows it's there and as I say she'll explain sometimes, she'll say "Oh they mental maths, I couldn't do it mum, you know how I've got the Down's Syndrome, oh it's hard" and I know that maths is one of the things, if she can't see it, it's harder for her to work out. But I wouldn't... I don't know how she sees...I mean she knows, I mean she gets taken out of the class for this, that and everything and she knows she goes here and does that but she's never actually said "why do I do this" "Do I have to get taken out of the class?" or, she just knows she goes for extra help, extra support, she knows that. I heard her telling someone in French she said the lady that was supporting her was retiring and she said "Lorraine's retiring, you know how she gives me a wee bit support because I've got Down's Syndrome", so...but she knows to a certain extent but, and we've never made her different, so, she, I don't think she does, I don't know, I don't think she does. She knows it's there but I explained it that everybody's got a wee something different and there's other kids get out the class, with no particular problems, but have to get taken out for extra support so... em I don't know that she sees that, to be honest.</p>	<p>associates DS with LDs.</p> <p>Social unawareness? - why not embarrassed + why doesn't notice difficulties with friends? DS doesn't bother her - doesn't realise social significance of it recognises learning difficulties, but not 'social difference' doesn't question why gets support in school - accepting understands what been told - DS but not difference</p>	<p>understanding DS in terms of LD.</p> <p>unawareness of social difference / meaning of DS.</p>
<p>ME: So she obviously knows about Down's Syndrome and she'll talk about that. Em, it was a few years ago you spoke about it. How did you decide to talk about it? Was that a difficult decision to make?</p> <p>MUM: No not really, as I said, I didn't want anybody saying it to her and her not knowing just the basic, you know, and that's, I think it actually started with my nephew who was a bit older, he was, he must have been about 9 or 10, maybe about 8 or 9 and somebody said something to him at school about, something along the lines of "your cousin doesn't walk right" or something and he got annoyed and said "Yes she does, she's fine and there's nothing wrong with her" and then we had to think "Well we'll need to tell him" but he didn't say I'm sure, what age is he now, 12? He must have been about 8 and we thought we really need to enlighten him a bit so we told him and then we told Lydia, just, we've never actually went into, Oh you've got an extra chromosome and all the rest of it, em, but I explained to her, as I said, my nephew has asthma, I've got diabetes, so we just said you've got something a wee bit different, it makes things a wee bit trickier for you, you</p>	<p>getting in there first with sensitive explanation adjusting explanation to suit her needs + level of understanding explaining in terms of benign social differences</p>	<p>Disclosure of DS - getting in there first taking social sig. of DS out of equation</p>

Interview 10: Lucy 15; sister Kate 19

<p>ME: That's brilliant, again, across the road.</p>		
<p>MUM: Yeah, both went there. Kate was in, going into P6 when Lucy started school, and, Kate loved that, because Kate had always said, "Mum she'll be going to my school won't she Mum, she will be come to my school". She loved that and, again, living here in the environment such a lot of people know Lucy from the school, so yeah they went to the same school.</p>	<p>Sister wanted Lucy to go to her school. Well known in local community - (seen positively)</p>	
<p>ME: Cool. How do you think Lucy sees herself in comparison with her big sister?</p>		
<p>MUM: I don't think Lucy sees herself any different at all and that's what I always would've wanted it to be anyway. Lucy doesn't see herself as any different from anybody. The only comparison that Lucy would ever say differs from her and Kate is that "Kate's so lucky, she's so skinny" because Kate is so super slim, it's just her natural, she's just really, really skinny and Lucy will say "I've got a big tummy" and I'll say "So has mummy, so has mummy. You know, some people have that but you're super healthy and you eat nice and healthy, you know we've turned the spare room into like a gym, we've got like a treadmill and a cross trainer and a gym ball. I thought, we'll go up there and do wer exercises and get superfit, other than that, no, with Kate and her friends coming over and you know they're up there doing their hair you know from like say 14 and up, Lucy's been in there with them, doing it all, the music, oh gosh, she could sing you any song that's on the MTV or the box or something, so she's grown up with that having an older sister and her friends over. Lucy thinks she's beautiful, but she is beautiful, but you know, she's, no, I only mentioned the words Downs Syndrome a few years back to Lucy and the only reason I done it then was because I was frightened she heard it from someone else and didn't understand it, so I sat her down and I went, I just told her when she was a little baby she was born with this em thing and it was called Downs Syndrome, but, it wasn't very important, she</p>	<p>Sees self no diff from sister - desirable. makes social comparisons on other aspects - weight Socialising with sisters friends - teenage gym activities grew up socialising w. sisters friends in home positive view physical self - looks attractiveness mentioned words 'DS' only did so to get in more first - taking control. frightened hear it elsewhere in less sensitive manner - DS not important - downplayed sig. of it</p>	<p>unawareness of difference from sibling awareness of other socially sig. attributes Sister's friends her friends too Disclaimer of DS - taking control Explaining DS, downplaying sig. of it</p>

Interview 10: Lucy 15; sister Kate 19

<p>didn't need to know much, it just meant it was a wee bit harder for her to learn things and if she would say "I can't read" I would say "you can read, you might not read the same as Kate but you can still read" or if she'll say "Oh I can't do..." A'll say "But you can, you just might not do it the same way as somebody else". But other than that, that's the only time it's been mentioned. But I don't, I've never focused on it, I've never made it a big deal, I've never wanted it to be who Lucy was. She always has been and always will be Lucy, she just happens to have Downs Syndrome, and I cannot abide it when people say "She is a Downs or he is a Downs", I have said to a few people "Please don't think I'm being rude, but please don't say that, because she is who she is, with this syndrome and he is who he is with the syndrome. A lot of people say there's a Downs girl, there's a Downs boy and, and that's not the case, because they're not that, so it's never been a big thing in my family, we've never, you know, really focused on the Down's Syndrome thing.</p>	<p><i>explained in terms of LD</i></p> <p><i>has expressed feeling incompetent - mum reassured that can just do differently.</i></p> <p><i>not wanted DS to be sig. in life - not sig. part of identity in family life</i></p> <p><i>angry at people who make DS central part of who she is - incidental labelling not defined by DS.</i></p>	<p><i>Explaining DS in terms of LD -</i></p> <p><i>not a big deal - not defined by DS in family - deliberate</i></p>
<p>ME: So how did she respond when you did say...had she heard of it?</p>		
<p>MUM: No, she just said "Oh yeah, whatever" and I'll say to her every now and again "Do you remember the word that Mum told you when you were a wee baby that you have?" and she'll go "Yeah" and I'll go, "What is it?" "Eh, Down's Syndrome" and I'll say "And do you know anybody else at all with it, is there anyone in your school with Down's Syndrome?" and she'll go "Eh, no, I don't think so". I don't tell her Caitlyn has because that's not my place, that's...but I ask her and she just says "I don't think so".</p>	<p><i>DS holds no significance or meaning for her.</i></p> <p><i>Doesn't identify herself as having DS. (from having met her mum, not obvious)</i></p>	<p><i>DS not significant/meaningful to child - just words.</i></p>
<p>Me: Yep...</p>		
<p>Mum: What she did do but, we were out at [local shopping centre] and there is a young girl with Down's Syndrome works in Primark and we were walking through [local shopping centre] and this girl's walking towards us and Lucy almost burst a blood vessel "Mum! Mum! Mum! She looks like</p>		

Interview 10: Lucy 15; sister Kate 19

<p>me, she looks like me" and I said, "Oh, so she does, she's got Down's Syndrome as well, [whispers] but you're prettier" Just to add a wee bit ...cause I'm her mum. And then she went "Oh" and then two seconds later, shwwwp, it was out of her head and that was her, she wasn't interested. But I think she, recognised that this person, kind of, she recognised herself in this person, but, other than that, no...</p>	<p>recognised DS in stranger + similarity to self.  so forgotten about quickly</p>	<p>Seeing Others w. DS. recognises features.</p>
<p>ME: So she hasn't done that with anybody else in school or...</p>		
<p>MUM: No...</p>		
<p>ME: Are there a lot of other children with Down's Syndrome at that school?</p>		
<p>MUM: No, no, the only other person Lucy has ever come into contact with with Down's Syndrome is Caitlyn. That's the only, I don't have friends, I don't know, I didn't go to groups when Lucy was wee and I didn't choose, she was in a mainstream nursery and then school, I didn't want to go to groups specifically aimed at children with special needs because, then I felt it was putting Lucy in a box and I at the beginning, I was obsessed with Lucy being my child as opposed to being a child with Down's Syndrome that everybody thought they had a wee kind of bit of. I needed to know that she was mine first and to be mine, the Down's Syndrome...because I don't have Down's Syndrome, I struggled because she had something that I didn't have, that I felt kind of made her a bit detached and different from me so I needed that not to be there, so she could just be mine then slowly I would kind of bring that bit back in, it was just strange, I didn't want people...some people think because you have a child with Down's Syndrome that it's their sort of God given right tae, they think they know you, as if they can go home and feel good about themselves because "Oh I met the, oh beautiful baby" as if she should've been an ugly baby, you know, and those people kind of, I realised that those people really kind of annoyed</p>	<p>One friend with DS  chase not to attend group especially for children w. disabilities - didn't want child to be different  felt best child to label  difficult to accept label / difference from self  difficulties coming to terms with social difference  felt like label took away individuality of daughter - referred to others prime non-proximal.  resentful / angered by reactions / comments of Others.</p>	<p>not wanting child to be defined by DS.  difficulties with label, social identity</p>



Interview 10: Lucy 15; sister Kate 19

<p>me a lot. You find things out about other people more.</p>		
<p>ME: Did you experience that a lot when she was a baby?</p>		
<p>MUM: Oh my gosh, yeah, yeah, you get the really ridiculous things, if I had a penny, I wish I had kept a diary, honestly, I wish I'd kept a diary, em, I even had a few people look in the pram and go "Oh, my gosh, are you sure, you would never know" and if I'd heard "God gives special babies to special people one more time" I think I might have punched somebody. So bloody patronising! You know, it really is. You think this little baby here is just a little baby, she has a syndrome attached to her, but she's no different from when Kate was in her pram, you know, no different, and I know that some people are a bit nervous and they don't know what to say, maybe if that had been me I would've been the same, but I know I would never have crossed a road to not look in the pram. I know that I would never have said some of the stupid clichés "God gives special babies..." "Oh they're so loving, oh your life will be blessed!" [makes a disgusted face and sound] And you just think, that's not what a new mum with a little baby who's got Down's Syndrome needs to hear. You just want people to go "Oh my God she's beautiful! What did she weigh? What did you call her?" You just want to hear the normal questions that would be asked of any baby. Keep your opinions to yourself, don't tell a new mum "You'd never know, are you sure, she looks just like any other baby" People don't need to hear those things. That, you know, some days it was good, and</p>	<p>anger at patronising comments of others.</p> <p>dealing with stigma as a new mother</p> <p>Stigma experienced as a new mother treated differently - resentful + sensitive to stigma attached to DS as a result.</p> <p>wanting normal questions - treated like mother of non-stigmatised child</p>	
<p>some days it was that bad, you would come in and just, you and I did struggle, I'm not going to lie, I mean it was a shock, a shock em, I wish I'd known then what I know now, or found at Lucy's first year, because, honest to God, I would not, I'm getting quite emotional saying this, I would not be without her, she's the absolute light of my entire family's life and I just, I say every family should have a Lucy, honest to God, every single</p>	<p>struggle with stigmatised identity of baby - shock of disability - past and present - mums difficult when baby? how dealing with stigma?</p>	