Influences in the Social Worlds of Children of Mothers with Intellectual Disability

By Susan Collings, BA (Hons), MPH

A thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Faculty of Health Sciences

The University of Sydney

March 2014

1

DECLARATION OF ORIGINALITY

I, Susan Collings, hereby declare that this submission is my own work and contains no material previously written or published except where acknowledged in the text. Nor does it contain any material which has previously been accepted for the award of another degree.

Susan Collings

March 11th 2014

ACKNOWLEDGMENTS

I now reach the formidable task of putting into words my heartfelt gratitude to all the people who helped me get here. My first expression of thanks rightly belongs to my supervisors, Professor Gwynnyth Llewellyn and Dr Rebekah Grace, whose guidance was a beacon when the path ahead became obscure. Gwynnyth, it has been my good fortune to have had a primary supervisor with your peerless knowledge about mothers with intellectual disability and willingness to share this with me. You have been such a huge part of this experience and it is impossible to fully express what completing this thesis means to me but I hope you know. Rebekah, your wit, warmth and encouragement are matched only by your sparkling intellect. I cannot imagine this experience without you so thanks for letting me persuade you to jump on board. It made all the difference.

To my husband Steven, words cannot describe the depth of my gratitude and love. You always believed that I could do this even when I doubted it myself and for that and so many other reasons this belongs as much to you as me. To our boys, Jude, Asher and Remy, whose own "middle childhoods" have taken shape with this thesis, thank you for being a constant reminder of what is truly important. I hope you managed to take something positive away from sharing your home with a PhD student for over four years. If it teaches you that the pursuit of something you believe in takes persistence and sacrifice then it will have been worthwhile.

Spending four years reflecting on mothers and children has kept my own mother front and centre in my thoughts. Mum, thanks for showing me that life never throws more our way than we can take. Your quiet strength, compassion and wisdom are

DEDICATION

I dedicate this thesis to the memory of my sister, Jennifer Anne Collings, whose life was just too short. I wish more than anything that she was with me when I reached the end of this journey. The world is so much poorer for the loss of her.

TABLE OF CONTENTS

9

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

Background

Our understanding of childhood for children of mothers with intellectual disability is based on a small number of retrospective accounts which point to some social difficulties, including bullying and stigma. Most research on mothers with intellectual disability and their children has focused on the possibility of developmental delay or abuse and neglect, with little consideration of children's experiences. The voices of children and their perspective on their lives are missing. The literature suggests that some mothers with intellectual disability experience social isolation, with few friends or family and reliance on formal services for support. However, it is not yet known whether a potentially restricted social context for these mothers influences the social experiences of their children. Children's social worlds typically expand during middle childhood as they start school, join community activities, play in neighbourhoods and spend time with peers. This study addresses a knowledge gap by exploring the social worlds of home, school, peers and neighbourhood for children of mothers with intellectual disability from their perspective to better understand the influences that shape their lives.

Aim and method

The study takes a standpoint informed by bioecological theory and the sociology of childhood. Together they provide a framework to explain the interconnected nature of children and their environment, whereby interactions in everyday contexts shape children's lives in ways they are uniquely positioned to identify. Seven children aged 7 to 11 years took part in semi-structured interviews and activities, such as drawing and photography, to explore their perspectives on everyday life. A narrative approach

14

was employed to analyse children's stories about what was important in the social worlds of home, school, peers and neighbourhood as this helped to explain how they perceived influences that shaped their social worlds.

Findings

The narratives of the children suggested that the social world of home influenced social interactions in other settings. When children perceived their home as predictable and secure, they spoke more confidently about exploring social interactions elsewhere. Children identified having support from another significant adult apart from their mother as key to a stable home social world. This person might be a father, family friend or relative, or a formal support worker. Children from homes that lacked predictability and another significant adult were more pessimistic about social interactions and experienced peer difficulties such as bullying. However, children whose homes lacked social support could counteract this by maximising the opportunities afforded at school. Some aspects of their social worlds that these children viewed as important, such as agency and safety, were typical in middle childhood however others, such as protectiveness toward their mother, were not.

Significance of the findings

The findings highlight that social worlds for children are not inevitably restricted when their mothers have intellectual disability, even when their mother faces restricted social circumstances. The findings challenge an assumption frequently found in the literature that mothers with intellectual disability may provide less than optimal environments for their children and, specifically, for their social worlds in middle childhood.
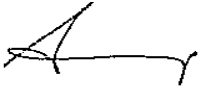
FACULTY OF HEALTH SCIENCES PUBLICATION STATEMENT

Statement from co-authors confirming the authorship contribution of the PhD candidate

As co-author of the paper Collings, S., & Llewellyn, G. (2011) Children of parents with intellectual disability: Facing poor outcomes or faring okay? *Journal of Intellectual & Developmental Disability*; 37(1): 65–82 I confirm that Susan Collings has made the following contributions: design of literature review, conduct of literature review and analysis of findings, interpretation and presentation of findings with support and advice, review of reviewer's suggestions and revision and submission of revised manuscript. In particular, the candidate's contribution to the following items should be noted:

- conception and design of the research

- analysis and interpretation of the findings

- writing the paper and critical appraisal of content

Signed…… *Gwynneth Llewellyn*   Date: 6th November 2013

Signed……   Date: 6th November 2013

CHAPTER 1: INTRODUCTION

1.1.   Statement of the problem

Little is known about the influence of the social context of mothers with intellectual disability on the social worlds of their children. Mothers with intellectual disability are thought to face social restrictions and it is important to understand if this social context poses similar restrictions for their children. Children of mothers with intellectual disability have been represented in the research literature as an "at-risk" group. The main risks addressed by research are developmental delay, neglect and abuse, and removal from parental care. Knowledge about their social worlds is based almost entirely on retrospective accounts of childhood from adult children. These studies include accounts of bullying, stigma and ostracism. However, these are accounts seen through adult eyes and present a perspective of childhood that is inevitably coloured by the passage of time. It is necessary to understand childhood as it is experienced in the "here and now" for children of mothers with intellectual disability.

1.2.   Significance of the problem

The depiction of children of mothers with intellectual disability as at-risk can itself pose a serious risk for them. Children of mothers with intellectual disability face a heightened risk of removal from parental care (Booth, Booth & McConnell, 2005; Llewellyn, McConnell & Ferronato, 2003; Taylor, Norman, Murphy, Jellinek, Quinn et al., 1991). This risk has been found to exist regardless of whether child protection allegations are substantiated (McConnell & Llewellyn, 2000). Discriminatory attitudes of judges and child protection workers have been implicated in the out-of-home placement outcomes for children of mothers with intellectual disability (McConnell,

17

Llewellyn & Ferronato, 2006; Ward & Tarleton, 2007). The prevailing "risk" perspective held about children of mothers with intellectual disability is driven by perceived and, in some cases, real concerns about their safety and wellbeing. This risk perspective, with the inevitable high proportion of children removed from their parents' care, has potentially profound implications for these children and their social worlds. This underlines the critical importance that their lives are presented from perspectives other than those which presume them to be at risk.

Research with children of mothers with intellectual disability that views them as agents who are engaged in reciprocal interactions in multiple, intersecting social worlds offers another perspective on their lives. The child's world can then be explored in terms of the dynamic interactions in the context of their particular environment. This perspective allows the emergence of a picture of the lives of children of mothers with intellectual disability based on their social interactions. Thus, this thesis set out to explore, from a child's perspective, the social worlds of home, school, peers and neighbourhood to understand the influences for individual children and those that illuminate influences at play in the lives of this group of children, more broadly.

1.3.   **Definitions of key terms**

1.3.1.   *Parents with intellectual disability*

Reaching a consensus on a definition of parental intellectual disability and determining accurate estimates of prevalence is an enormous challenge for many reasons, including the size of this population and changes in the terminology and criteria used to determine intellectual disability. Recent United Kingdom research based on a representative population-based sample estimates that they make up just

over 1% of the parent population (Emerson & Bringham, 2014) and a Australian

population-based household survey estimates that 0.77% of children have a parent

with intellectual disability (Man, Llewellyn, & Wade, 2013). Despite being relatively

small in population terms, families headed by parents with intellectual disability are

likely to be found in most health and social welfare caseloads, warranting attention

from policymakers (IASSID SIRG on Parents and Parenting with Intellectual

Disability, 2008). In Australia, child and family service providers expressed concerns

about their capacity to respond effectively to the often complex needs of this

disadvantaged parent group. This led the Commonwealth Government to fund a

specific initiative to address this issue. The strategy, known as Healthy Start, was

established almost a decade ago (see www.healthystart.net.au) and continues to

inform policy and practice in this field and to promote evidence-based practice.

It is widely accepted by experts in the field that most parents labelled with intellectual

disability have mild to borderline cognitive limitations (IASSID, 2008) and are

unlikely to meet a clinical criterion for diagnosis of intellectual disability. In addition,

IQ tests are less frequently employed today meaning that many parents with

intellectual disability may never have had an IQ test. Indeed, it is well established that

IQ alone is unreliable for predicting parental capacity (IASSID, 2008; Tymchuk,

2001; Tymchuk & Andron, 1990). Researchers have long known that adults with

intellectual disability may assume a "cloak of competence" to avoid the stigma

associated with being labelled "intellectually disabled" (Edgerton, 1967). Today, a

social systems definition (Mercer, 1973) is often used to determine parents with

intellectual disability as this definition acknowledges that many adults with

intellectual disability are not, or do not wish to be, identified as having an intellectual

disability. Mercer (1973) defines intellectual disability as a label applied to a person

who occupies a particular role in the social system that is irreducible to IQ, adaptive behaviour or the extent of organic impairment alone. The so-called "social systems" definition of intellectual disability permits researchers and service providers to identify people with intellectual disability by reference to significant others in the social system.

1.3.2. *Middle childhood*

The term *middle childhood* refers to a stage of childhood that developmental psychologists associate with the period between approximately 6 and 12 years of age and which has gained increasing research attention over recent decades (see Collins, 1984). For most Western developed nations, middle childhood corresponds with the age at which children start school and precedes the onset of adolescence (Huston & Ripke, 2006).

1.3.3. *The social worlds of children*

The concept of 'social worlds' is used in this thesis to describe influential domains of everyday life for children. I use the term 'social worlds' to describe the contexts in which children participate in interactions through which they learn about their world. Social worlds are necessarily plural since children's social contexts are multiple, often overlapping, and it is movement between contexts that can promote important learning opportunities. Social worlds include, but are not restricted to, physical settings such as the home. Peers, for example, are an important context in which children learn about themselves in relation to the world in which they live, and this is a social world that is irreducible to any single physical setting. Research literature highlights that home, school, peers and neighbourhood are important social contexts in middle childhood

and, given that this life stage is the focus of the thesis, they are an appropriate research focus for the study.

1.4. **Existing knowledge**

1.4.1. *The social context of mothers with intellectual disability*

The literature that addresses the social context of mothers with intellectual disability suggests that the lives of some of these mothers are socially restricted. Mothers with intellectual disability have small social networks and these are thought to be typically comprised of family members or service providers (Llewellyn, 2002, 2004; Stenfert-Kroese, Hussein, Clifford & Ahmed, 2002). Several researchers have noted the absence of friends or neighbours in these support networks (Ehlers-Flint, 2002; Llewellyn, 1995; Llewellyn, McConnell & Bye, 1998; Llewellyn & McConnell, 2002; Stenfert-Kroese et al., 2002). Some mothers perceive the support available as unhelpful, insufficient or judgmental (Ehlers-Flint, 2002; Feldman, Varghese, Ramsay & Rajska, 2002; Stenfert-Kroese et al., 2002; Tucker & Johnson, 1989). Single mothers with intellectual disability may need to rely on formal support and these support networks may be less enduring than family-based networks (Ehlers-Flint, 2002; Llewellyn & McConnell, 2002, 2004). Mothers with intellectual disability who are socially isolated or who do not regard their support networks as adequate may experience greater stress (Aunos, Feldman & Goupil, 2008; Feldman et al., 2002; Feldman & Walton Allen, 1997; Stenfert-Kroese et al., 2002).

A small number of studies have examined the effect of the social context of mothers with intellectual disability on their children (Aunos et al., 2008; Feldman & Walton Allen, 1997; Wade, Llewellyn & Matthews, 2011; Wise, 1997). Wade, Llewellyn and Matthews (2011) recently found that a direct association between parenting practices

and child outcomes was mediated by the indirect influence of social support on maternal mental health.

1.4.2. *Children of mothers with intellectual disability*

The majority of research about children of mothers with intellectual disability has examined the likelihood of developmental delay, abuse and neglect, and child removal, primarily for children younger than five years. In general, the literature presents children of mothers with intellectual disability as being at risk. An established finding is that they are overrepresented in child removal cases (Booth et al., 2005; Llewellyn et al., 2003; Taylor et al., 1991). Closer inspection of the evidence suggests that the risk of neglect and abuse cannot be easily disentangled from contextual factors such as social isolation and socioeconomic disadvantage. Children of mothers who themselves have experienced childhood abuse and neglect, have mental illness or misuse substance are at increased risk of neglect and, more rarely, abuse (Gillberg & Geijer-Karlsson, 1983; Glaun & Brown, 1999; McGaw, Shaw, Beckley, 2007; Seagull & Scheurer, 1986). The risk of developmental delay is not established, with contradictory findings at this time. In half of the studies investigating developmental outcomes, development of most of the children was found to approach population norms (Aunos et al., 2008; McConnell et al., 2003; McGaw et al., 2007). Not surprisingly, higher rates of delay were found in studies conducted with children already suspected of developmental delay or found to have existing disability (Feldman, Sparks & Case, 1993; Keltner, Wise & Taylor, 1999). Later research identified disproportionately high rates of birth complications among the children of mothers with intellectual disability, which is thought to explain earlier findings about their poorer developmental outcomes (McConnell, Llewellyn, Mayes, Russo & Honey, 2003; McConnell, Mayes & Llewellyn, 2008).

22

A small number of studies have explored childhood from the perspective of adults looking back (Booth & Booth, 1998; O'Neill, 2011; Ronai, 1997; Traustadóttir & Sigurjónsdóttir, 2005) or, more rarely, children of mothers with intellectual disability(Faureholm, 2010). These are predominantly retrospective studies using narrative or exploratory research methods. Some accounts report that children were supported by extended family (Booth & Booth, 1998; Traustadóttir & Sigurjónsdóttir, 2005) and other studies indicate socially isolated childhoods (Faureholm, 2010; O'Neill, 2011; Ronai, 1997). These accounts of childhood suggest that some children faced social difficulties such as stigma, bullying and ostracism.

1.4.3. *Mothers in the social worlds of children in middle childhood*

Social worlds inevitably overlap and mothers are a part of the many of the social worlds of their children, making it difficult to disentangle the influences that shape the social worlds of children from those that are influential in the lives of their mothers (Bronfenbrenner, 1979). In middle childhood, children begin to engage in more social worlds beyond the home such as schools and neighbourhoods, and to spend time with peers and nonrelated adults such as teachers and the parents of their friends. Research demonstrates, however, that mothers remain an important influence on the social worlds of their children in middle childhood. This influence is exerted directly through the influence of social support for mothers on their parenting and the influence of mother-child interactions on peer interactions (Attree, 2005; Blair, Perry, O'Brien, Calkins, Keane et al., 2013; Grimes, Klein & Putallaz, 2004; Schneider, Atkinson & Tardif, 2001). Mothers exert an indirect influence on the social worlds of their children through the access they provide to social networks and their management of peer contact (Grimes et al., 2004; Ingoldsby & Shaw, 2002; O'Neil, Parke, & McDowell, 2001; Uhlendorff, 2000). Peers become increasingly influential

23

in the social worlds of children during middle childhood (Berndt, 2004; Rubin, Bukowski, & Parker, 2006; Seibert & Kearns, 2009). High-quality friendships may buffer children against some forms of family adversity and peer difficulties (Criss, Pettit, Bates, Dodge, & Lapp, 2002; Rubin et al., 2006a; Schmidt & Bagwell, 2007).

In middle childhood, children deepen their neighbourhood connections and value neighbourhoods that provide access to peers, safe places to play, and social activities (Milne, 2009; Rogers, 2012; Scourfield, Dicks, Holland, Drakeford, & Davies, 2006; Spilsbury, Korbin, & Coulton, 2009). Findings about restriction of the social worlds of children from disadvantaged neighbourhoods may be relevant for the current study in light of research that reports an association between intellectual disability and socioeconomic disadvantage (Emerson, 2007). Children may perceive their disadvantaged neighbourhood as lacking safe and appropriate spaces to play, and this can affect their wellbeing and satisfaction (Carvalho, 2012; Mier, Lee, Smith, Wang, Irizarry et al., 2013; Rogers, 2012). Mothers living in disadvantaged neighbourhoods who perceive safety risks and see peers as a subversive influence may restrict their children's contact within the neighbourhood (Ingoldsby & Shaw, 2002; O'Neil et al, 2001). A review of studies exploring the social context of mothers with intellectual disability found that most of those studies were conducted with mothers from disadvantaged backgrounds. Thus, the findings reported on the socially restricted lives of mothers with intellectual disability reflect primarily the situation of mothers from disadvantaged circumstances.

1.5.   Gaps in the literature

This study addresses the limited knowledge about the social worlds of children of mothers with intellectual disability. In so doing, it also provides knowledge about the

influence of the mothers' social contexts on their children's social world. This study contributes to an assumption often found in the literature – where it is known that the social context for some mothers is restricted and assumed that this influences the social worlds of their children, although this has not been shown Knowledge about the social context of mothers with intellectual disability comes from studies conducted to understand their social support and social networks, social relationships, social skills and community participation. Few studies in this literature have investigated child outcomes and, to date, only one demonstrates a direct association between the social context of a mother and the physical and cognitive wellbeing for her child (Wade et al., 2011). That study included only young children under six. Social worlds for children expand in middle childhood and the influence of maternal social support on children in this life stage may be different from that in early childhood, due to the increased influence of other social contexts such as school, peers and neighbourhood.

To date, knowledge about the children of mothers with intellectual disability is based largely on findings from studies primarily conducted to examine developmental outcomes and safety risks for children. This focus results in four significant gaps in understanding these children's social worlds in middle childhood. First, research has focused on development of young children and little is known about their lives in middle childhood. Second, a preoccupation with examining the likely risks faced by children of mothers with intellectual disability means that their social relationships have been largely overlooked. Third, knowledge about childhood for children of mothers with intellectual disability is based only on a small number of retrospective accounts and one prospective account (available however only in summary form in English). Fourth, current knowledge about how these children perceive their social worlds in middle childhood is under-developed. Apart from the one prospective

25

longitudinal study conducted with Danish children (Faureholm, 2010), the voices of children are missing from the literature.

1.6. **Theoretical background to the study**

As stated, this study draws from bioecological theory (Bronfenbrenner & Ceci, 1994), in which social environments are viewed as presenting opportunities that can invite, permit, or inhibit children's engagement in interactions and activities that shape their social worlds (Bronfenbrenner & Morris, 1998). In middle childhood, children engage in more social worlds away from home and the influences that shape their social worlds multiply. From the earliest formulation of his model, known then as *ecological theory*, Bronfenbrenner (1979) stressed that interactions between children and their mothers are a primary context for formative early learning opportunities. However, according to Bronfenbrenner, to view the mother-child relationship in isolation from the environment in which it is experienced inevitably distorts the influence of this context and overlooks other potentially influential contexts. It also ignores the bidirectional nature of social interactions whereby a dynamic interplay takes place between the particularity of a child and that child's particular social environments.

Consistent with the sociology of childhood (James & Prout, 1997), in this study children are seen as best placed to provide a reliable perspective on their social worlds. Childhood is experienced differently depending on the historical, social and cultural context of particular children (Corsaro, 2011; James, 2005). The sociology of childhood calls for research that recognises the diversity of children's life experiences (James, 2005; Jenks, 1996, 2000). This framework offers a sound theoretical base for research that sets out to hear children's perspectives on their lives (Christenson & James, 2000; Green & Hogan, 2005; Hallet & Prout, 2003). It offers a new approach

to research about the lives of children of mothers with intellectual disability. To date, they have been viewed as at-risk because of negative stereotypes about the parenting provided by their mothers, but this perspective has to a large extent ignored parental and family contextual features such as socioeconomic status and social support. The approach used in this study comes from the foundation underpinning the sociology of childhood, that children are reliable informants about their lives. It is presumed, therefore, that information that presents children's perspectives on their lives can illuminate influences in their social worlds, which include social worlds which they share with their mothers with intellectual disability and those which they do not, such as school and friends.

1.7.   **Aim of the study**

This study explores how children of mothers with intellectual disability perceive their social worlds in middle childhood. With evidence suggesting that some mothers with intellectual disability face social restrictions, it is important to differentiate the social context of mothers and their children and reject the presumption that a mothers' social context will be mirrored in that of their child or children. This is salient in the face of persistently negative stereotypes about parenting by these mothers that presents their children as at risk. Presenting a child's perspective follows from the theoretical perspective that children are deemed to be social agents in the interactions that shape their social worlds.

1.8.   **Research questions**

Two research questions underpin this study. These are 1) what are the influences in the home, school, peers and neighbourhood social worlds of children of mothers with

intellectual disability and 2) what influence does a potentially restricted social context

for mothers with intellectual disability have on the social worlds of their children.

CHAPTER 2: THE SOCIAL CONTEXT OF MOTHERS WITH INTELLECTUAL DISABILITY

2.1.   **Introduction**

The purpose of this chapter is to review studies that examine aspects of the social context of mothers with intellectual disability or that report an association between the social context of these mothers and outcomes for their children. For the purpose of this review, social context refers to environmental influences that shape the context in which mothers raise their children, such as social support and socioeconomic status. The review establishes the strength and limitations of the evidence and discusses gaps in knowledge. Together with a review of literature about the social and developmental outcomes for this group of children (see Chapter 3), this chapter establishes current knowledge about one aspect of the social worlds for children, namely the home environment they share with their mother, by exploring aspects of her social context. It also points to what is not yet known about mothers' social context or how it influences children, particularly in terms of their social experiences in middle childhood.

2.2.   **Method**

A literature search was carried out using Proquest (Central), Medline, psychINFO, PsychCRITIQUE, Web of Knowledge electronic databases between June 2012 and November 2012. The search terms used were *mothers* and *parents* combined with *intellectual disability/ies* or *learning disability/ies* combined with *social isolation, social support* and *social networks.* This search yielded seven studies. A secondary search of their references identified ten additional studies. An electronic alert about new publications, received in May 2013, revealed that a systematic literature review

had been undertaken since this review was completed. Wilson, McKenzie, Quayle and Murray (2013) reviewed seven parenting interventions designed to teach parenting skills and strengthen social relationships for parents with intellectual disability. The only two studies in their review that addressed social relationships had already been identified (McGaw *et al.,* 2002; McConnell & Llewellyn, 2010). It must be noted that, although the focus of this review in this chapter is mothers with intellectual disability, some of the studies reviewed also included fathers or did not report parental gender. In the former case, mothers were in the majority in those studies. In the latter case, due to recruitment via parenting programs, it can be reasonably assumed that a higher proportion of mothers than fathers took part. For these reasons it was deemed unnecessary to restrict the review to studies conducted solely with mothers.

Analysis of the 17 studies makes clear that investigation of the social context of mothers with intellectual disability has been considered in relation to four aspects of their social lives. Studies have addressed research questions about social support and social networks, social skills, social relationships and community participation. Another small group of studies report on associations between aspects of mothers' social worlds and child outcomes. These categories are used to structure this literature review. Table 2[1] presents a summary of the characteristics of the 17 studies reviewed in this chapter.

---

[1] Table 1 appears in Chapter 3. Table 1 was included in a publication and therefore table numbers cannot be reordered to reflect their chronology in the thesis.

Table 2. Studies about the social context of mothers with intellectual disability and child outcomes

Year	Author	Purpose	Design	Sample	Method	N=mother	N=child	Maternal features	Child features	Parental descriptor
Studies about social support and social networks										
2002	Llewellyn & McConnell	To explore the views of mothers with ID & significant others about their support needs	Descriptive	Formal services	Semi-structured interviews using Support Interview Guide (SIG, Llewellyn & McConnell, 1999)	70	not reported	57% couple relationship; 90% English speaking background; low SES	pre-school aged	mother
2002	Stenfert-Kroese, Hussein, Clifford & Ahmed	To examine the impact of social support on wellbeing of mothers with ID	Descriptive	Formal services	Semi-structured interviews; Measures: Affect Balance Scale (adapted from Bradburn,1969), Self-Esteem Questionnaire (ad. Rosenberg,1965), Assertiveness Questionnaire (ad. Gambrill & Richey, 1975).	15	32	25-49 years; 80% in couple relationships; low SES	1-17 years	mother
2002	Feldman, Varghese, Ramsay & Rajska	To examine the association between stress, social isolation & mother-child interactions for mothers with ID	Correlational	Formal services	Measures: Telleen Parent Social Support Index (Telleen 1985); Interpersonal Support Evaluation List (ISEL; Cohen & Hoberman, 1983); Parenting Stress Index (Abidin 1990); mother-child interaction checklist	30	62	50%+ in couple relationship; low SES	8 years (average), ratio boys: girl = 2:1	mother

					(Feldman et al. 1986, 1989, 1993).					
1989	Tucker & Johnson	To investigate social support for mothers with ID	Descriptive	Formal services or known to researchers	Semi-structured interviews and observation over 2 years	12	25	8 in couple relationship, 4 single parents	age unknown	parent
2004	Llewellyn & McConnell	To develop a typology of social networks for mothers with ID	Descriptive	Formal services	Based on findings from earlier studies (Llewellyn.1995; 1997; Llewellyn et al., 1998; Llewellyn & McConnell, 2002)	70+	not reported	not reported	pre-school aged	mother
2008	Traustadóttir & Sigurjónsdóttir	To explore family support networks for mothers with ID over 3 generations	Exploratory	Formal services or known to researchers	In-depth interviews, observation	18	38	20-80 years old;	age unknown	mother
Studies about social relationships										
2002	Ehlers-Flint	To explore the views of mothers with ID about parenting	Exploratory	Formal services	Semi-structured interviews; Measures: Parenting Attitude and demographic questionnaire; Inventory of social contacts	20	not reported	50% in couple relationship; low SES; 50%+ history of abuse.	age unknown	mother
1995	Llewellyn	To explore the views of parents with ID on parenting and relationships	Exploratory	Formal services or disability advocacy organisations	In-depth interviews and observations over 2 years	6	9	6 couples took part in study	1-14 years; 4 developing normally; 5 developmental delay	parent

1998	Llewellyn, McConnell & Bye	To examine the support needs of parents with ID	Descriptive	Formal services	Semi-structured interviews; survey about child care, domestic needs, social & community involvement	47	not reported	66% in couple relationship; majority English-speaking backgrounds	42% parents had children 5-12 years	parent; 40 mothers

Studies about social skills

2002	McGaw, Ball & Clark	To evaluate the effectiveness of a group training program to enhance social skills	Experimental	Formal services	Semi-structured format; Judson Self-rating scale (Judson & Burden, 1980); Behaviour Problem Index (BPI; Cunningham et al. 1986); The Malaise Inventory (Rutter et al. 1970); Social Changes Questionnaire1 (Ball 1995)	22	32	16 had partners; including 5 couples in the groups. 95% dependent on government payments; 1 employed. Mean= 30 years old.	Experimental group: 4 yrs; Control group: 3.3 yrs. History of child removal: 10 parents	parents- 14 mothers, 8 fathers
2003	Booth & Booth	To support mothers with intellectual disability to develop self-advocacy skills	Evaluation	Formal services	Questionnaire; individual portfolios reviewed	31	24	mothers with ID	age unknown	mother
2010	McConnell & Llewellyn	To broaden social networks & increase community participation for mothers with ID	Intervention	Formal services	Measures: Tilden interpersonal relationships inventory (Cohen & Hoberman, 1983); Scales of mastery and constraints (Lachman & Weaver, 1998); Depression, Anxiety and Stress Scales	32	not reported	4 mothers and 1 father with ID	age unknown	mother

					(DASS-21, Lovibond & Lovibond, 1995)					

Studies about community participation

| 2010 | Llewellyn & Gustavsson | To explore how mothers with ID build community relationships | Exploratory | Known to researchers | Semi-structured interviews | 5 | 8 | 2 single, 1 married, 2 recently separated | 0-14 years | 4 mothers, 1 father |

Studies about the influence of the social context for mothers on child outcomes

| 1997 | Wise | To examine an association between environment, social support & parent-child interaction | Correlational | community sample | Analyse data from Keltner (1993). Measures used: HOME Inventory (Caldwell & Bradley 1984); Perceived Maternal Social Support (MSSI); US Census 1993; JCC/MEO (1990) | 100 | 100 | 70% African-American; 75% single mothers; low SES and 25% living in poverty | 3 months | mother |
| 1997 | Feldman & Walton-Allen | To examine the association between poverty, maternal ID and child outcomes | Correlational | Formal services | Measures: Parenting Stress Index (Abidin 1990), HOME Inventory (Caldwell & Bradley 1984; WISC-R (Wechsler, 1974); child behaviour checklist (Achenbach & Edelbrook,1981) | 27 | 27 | 50%+ in couple relationship; Anglo background; low SES | 6-12 years | mother |

Year	Authors	Aim	Design	Setting	Measures			Sample	Child age	Participant
2008	Aunos, Feldman & Goupil	To examine the relationship between maternal wellbeing for mothers with ID and child behaviour outcomes	Correlational	Formal services	Measures: Parenting Stress Index (Abidin1990), parent mental health (SF-36, Ware et al. 2000); HOME Inventory (Caldwell & Bradley 1984); Child Behaviour Checklist (Achenbach 1988, 1991).	32	32	70% in couple relationship; low SES	2-13 years	mother
2011	Wade, Llewellyn & Matthews	To examine the association between environmental variables, parenting practices and child wellbeing	Correlational	Formal services	Measures: Parenting practices & social support (LSAC; Zubrick et al., 2008), SEIFA index of disadvantage (ABS, 2001); parent health survey (SF-12; Ware, Kosinski, & Keller, 1998); Parents Evaluation of Developmental Status (PEDS) for children (Glascoe, 2006)	120	120	50+% single mothers; Low SES: 85% dependent on government payments; High proportion unemployed (90%),	under 6 years	parent (93% mothers)

Abbreviations used: ID (intellectual disability), SES (socioeconomic status).

2.3. Studies about the social context of mothers with ID

2.3.1. *Studies about social support and social networks*

Over a third of the studies reviewed investigated the social support or social networks of mothers with intellectual disability. As a focus of research attention, it is appropriate to begin by reporting findings from these studies. Support network size was specifically addressed in one study and the relationship between social support and maternal wellbeing or parenting competence investigated in three others. The last two studies in this category explored the difference between the social networks of mothers and the role of extended family support.

Llewellyn and McConnell (2002) investigated the size of the support networks of mothers with intellectual disability. They used a purpose-designed interview guide to distinguish proximal from remote contacts for 70 mothers with intellectual disability with pre-school aged children. The perceived utility of network ties was also investigated. Network ties were groups that comprised a support network, such as family members or service providers. Supportive connections or ties were defined as the individuals or groups, such as a sister and brother-in-law, whom mothers identified as supportive. Mothers with intellectual disability had, on average, eight supportive connections. One in four mothers identified no supportive ties with friends or neighbours. The same proportion regarded formal services as their primary supportive connection. Mothers who lived alone with their children reported significantly fewer supportive ties than other mothers. Their relationships, most of which were with formal services, were significantly less enduring. Half of the mothers had family-centred support networks. These mothers, particularly those with partners, did not feel

close to formal services or comfortable asking for their help. In contrast, mothers living alone were comfortable asking for and receiving support from formal services.

Three studies examined the impact of social support on the wellbeing or parenting skills of mothers with intellectual disability. Stenfert-Kroese, Hussein, Clifford and Ahmed (2002) examined the impact of social support on the wellbeing and parenting satisfaction of 15 mothers with intellectual disability. Mothers and their 32 children, aged from 1 to 17 years, were recruited through formal services. The majority (80%) of mothers lived with a partner. Semi-structured interviews and measures of support network satisfaction and self-esteem were undertaken. The authors found that mothers' social networks were most likely to be comprised of extended family. The majority of mothers had, on average, seven social contacts, five of which were regarded as helpful. Unhelpful contacts were described as irregular, infrequent or unresponsive to the support needs identified by mothers. Almost half of the mothers viewed their support as helpful. Mothers continued to accept support they viewed as unhelpful, which may suggest that they perceived themselves as lacking other options. The study reported a significant association between maternal self-esteem and social network size. Network size and how recently supportive contact had been received predicted maternal wellbeing. The authors noted that the lack of friends found in this study was similar to that of childless people with intellectual disability. Only one in three mothers reported having friends, confirming the earlier findings of Llewellyn and colleagues that mothers with intellectual disability lack this source of social support (Llewellyn, 1995; Llewellyn & McConnell, 2002; Llewellyn et al., 1998).

Feldman, Varghese, Ramsay and Rajska (2002) examined the relationship between stress, social isolation and mother-child interactions among 30 socio-economically

disadvantaged mothers with intellectual disability and their 62 children whose average age was 8 years. The study involved semi-structured interviews and used measures of parenting stress and social support. The authors reported that mothers may perceive themselves as having insufficient social support regardless of the actual level of support available. Both perceptions of support needs and maternal stress increased as children grew older. On average, perceived support was moderate and satisfaction with social participation was low. Satisfaction with social support was positively correlated with the positive behaviours displayed by mothers in interactions with their child. No assessment of the impact on children of maternal behaviours in mother-child interactions was undertaken. Mothers identified their main source of support as service workers, followed by friends. Family was ranked as the third source of support. The findings suggested that network size is not an independent predictor of support satisfaction or perceived support needs for mothers with intellectual disability.

Tucker and Johnson (1989) examined the social networks of 12 parents with intellectual disability to understand which characteristics of social support build or undermine parenting competence. Although parental gender was not provided, a high proportion of participants were likely to be mothers, due to recruitment through a parenting program for parents with intellectual disability. Eight parents lived with their partner and four either lived alone or with extended family. Semi-structured interviews and home observations were conducted with parents and family members. The authors found that parents with intellectual disability received support that either promoted parenting competence or inhibited them from acquiring parenting skills. Two thirds of parents received competence-promoting support.

Tucker and Johnson (1989) reported that the support people who promoted competence were in a position to mobilise additional resources when necessary and had fewer other environmental stressors. They also exhibited a strong sense of responsibility for the parent with intellectual disability and viewed their role as enabling them to gain independence. Parents who received support identified as confidence-inhibiting were more dissatisfied with their support networks and perceived themselves as insufficiently supported. In these cases, support people viewed the parent with intellectual disability as incapable of managing on their own, and believed that a risk to the safety of children in the care of the mother with intellectual disability existed. However, confidence-inhibiting support people often felt overburdened by other responsibilities and had fewer resources to assist them in their support role.

Taken together, the studies reviewed so far suggest that social support that is ill-matched to the needs of mothers with intellectual disability can hamper their parenting competence and wellbeing. Llewellyn and McConnell (2004) examined the findings of their earlier studies (Llewellyn, 1995; Llewellyn & McConnell, 2002; Llewellyn et al, 1998, also included in this review) to explore the home environment in which mothers with intellectual disability learn mothering skills. The authors found that some types of households and support networks provided greater opportunities for the promotion of mothering skills than others. The three distinct household types identified were a mother living with her partner (dispersed family centred network), a mother living with a parent or parental figure (local family centred network) and a single mother living alone with her children (service centred network). Friends and neighbours were notably absent from the support networks of all three types of household.

Llewellyn and McConnell (2004) found that mothers with partners had the largest family-centred networks because they typically had access to two sets of extended family support. The social relationships of these mothers tended to be long-term and stable. They were reluctant to ask for or accept formal support. Family was also central to the support networks of mothers who lived with their parent or a parental figure. Similarly, their social relationships were likely to be enduring, and formal services were less willingly accepted. Mothers who shared a house with a partner, parent or parental figure tended to express a desire for greater parenting independence, which might explain their reluctance to accept formal services. Of the three groups, mothers who lived alone with their children were found to be the most socially isolated and vulnerable. Their small networks were comprised of a high proportion of formal services. This made it more likely that their social relationships were less secure or long-term. As the study made clear, substantial differences in the support and learning opportunities available in these three types of households were evident.

Llewellyn and McConnell (2004) indicated that extended family can provide mothers with intellectual disability with stable and long-term support. The role of extended family support was investigated by Traustadóttir and Sigurjónsdóttir (2008). Eighteen mothers from three generations took part in the study. Mothers were known to the researchers or recruited through formal services. In-depth interviews were conducted with three elderly, two middle-aged and 13 young mothers with intellectual disability. Some of their partners, children and extended family also took part in interviews. Of the 38 children born to these mothers, 15 had been removed at birth or during childhood. None of the five children born to the youngest group of mothers had been removed.

The study reported a positive shift in social attitude towards parenting with intellectual disability in Iceland over the six decades since the oldest women became mothers. For example, the elderly mothers had lacked access to formal services and had depended on family support to raise their children. In contrast, the young mothers received formal support that acknowledged the primacy of their parenting role. The study suggests that, at least in Iceland, there has been a shift in the social acceptability of parenting by women with intellectual disability. Despite this, all the young mothers expressed a fear that their children would be removed by child protection authorities. Some young mothers reported that formal services used this fear to gain their compliance about accepting the recommended services. The availability of extended family support, particularly from a female relative, influenced whether mothers were able to retain custody of their children. Support included emotional and practical assistance, protection from professional scrutiny and advocacy to access services.

2.3.2. *Studies about social relationships*

Three studies presented findings about the social relationships, support needs and parenting of mothers with intellectual disability from a mother's perspective. Elhers-Flint (2002) examined the perceptions of 20 mothers with intellectual disability about parenting and social support. The mothers, who were from low socioeconomic backgrounds, were known to a formal service for people with intellectual disability. Half of the mothers lived with partners, four lived with relatives and six lived alone with their children. The study found that mothers held positive views about parenting. They perceived more support than interference from their social networks and were satisfied with formal services. Half of the mothers reported a history of victimisation or abuse, typically at the hands of immediate family or partners. Mothers who had experienced victimisation or abuse had few positive parenting role models and two

41

thirds felt criticised by family members. However, one in three mothers who did not report childhood abuse also perceived their family to be critical of their parenting. Given this finding, the authors noted that mothers might have exaggerated their social network satisfaction. Reluctance to report dissatisfaction, or a perception that formal services were less judgmental of their parenting than family members, might also explain their reported satisfaction with formal services. The authors noted that many mothers reported less stress from community interactions than from other social relationships. However, given their reportedly low levels of community engagement, they might have had fewer opportunities for negative interactions. A finding in this study about the limited community involvement of many mothers echoed that reported in other research (Feldman et al., 2002; Llewellyn et al., 1998; Stenfert-Kroese et al., 2002).

Llewellyn (1995) explored the views of parents with intellectual disability about their parenting and social relationships. The study involved in-depth interviews and observations with six couples conducted over a 2-year period. In four of the couples, both parents had intellectual disability. Parents were recruited through formal services and advocacy organisations. The study identified three patterns regarding social support. First, family was found to be the most common source of support, followed by formal services. However, not all parents viewed their families as supportive. A second pattern concerned parental responses to social support. Parents frequently reported that social support was unhelpful or intrusive and saw helpful support as that which matched their perceived support needs. New parents were more likely than those with older children to unquestioningly accept support from family and formal services. A third pattern concerned social isolation. Few parents in this study included friends or neighbours in their support networks. Eight out of ten parents were unable

to name a friend they could call on for assistance and no parents knew any other parents with intellectual disability.

Llewellyn, McConnell and Bye (1998) examined the perceived support needs of parents with intellectual disability and the views of significant others and formal services in their lives about the parents' support needs. The study included 40 mothers and seven fathers. Formal services were found to perceive parents as having greater support needs than the parents themselves. This could indicate that parents had unrealistic views or that formal services underestimated their parenting capacity. Parents, formal services and significant others agreed that the main purpose of support was to address child care needs. However, from parents' perspective, their greatest unmet need was community participation. Parents saw a need for vocational options and skills to access services, meet people and make friends. Formal services tended to overlook the need for parents to gain skills that would to equip them to participate in their community. Echoing other research about the apparently small social networks of some parents with intellectual disability (Ehlers-Flint, 2002; Llewellyn, 1995; Llewellyn & McConnell, 2002, 2004; Stenfert-Kroese et al., 2002), the authors noted that almost a third of parents could not nominate a significant other to take part in the study.

2.3.3. *Studies about social skills*

Three studies reported on program interventions to address social skills deficits for mothers with intellectual disability. The first to be reviewed here evaluated a program that addressed this deficit was conducted by McGaw, Ball and Clark (2002). They evaluated the effectiveness of a group training program to increase the social skills of 22 parents with intellectual disability, 14 of whom were mothers. Eleven parents were

allocated to a 14-week group-based parenting program including individual home-based instruction. Eleven parents received the home-based component only. Pre, post and 27 week follow-up measures of parental self-concept, perceived quality of parent-child relationship, and satisfaction with partners, family members and professionals were undertaken.

Overall, the findings indicated that parents who completed group training had a more positive view of themselves. Two thirds of the parents reported making positive life changes following group training. Single parents were significantly more vulnerable to negative self-concept than those with partners. They viewed the quality of their relationships with their children and significant others less favourably than mothers with partners. The perception of parent–child relationships and rating of their child's behaviour remained stable for parents assigned to group training. However, all these parents made new friendships, including those they formed outside the group. In contrast, no parent who received the home-based training only reported making any new friends. The authors noted that children of parents who took part in the group training may have benefitted from improved parent–child relationships and from their parents' improved self-concept.

A year later, again in the UK, Booth and Booth (2003) reported on a program that supported mothers with intellectual disability to develop self-advocacy skills. The Supported Learning Project (SLP) used a group-based approach to provide guidance and support for mothers with intellectual disability to access vocational options and community activities. Over a 2-year period, 31 mothers participated in the program. On average, nine mothers and four of their pre-school aged children attended a weekly group. During or after completing the program 13 mothers gained paid or voluntary

work, 15 joined courses and seven initiated positive changes to their living arrangements. Eighteen mothers completed a post-program questionnaire and the majority reported having found the support group beneficial. Apart from the formal instruction, mothers noted that other participants had been a source of learning and support.

More recently, McConnell and Llewellyn[2] (2010) evaluated a facilitated group-work program, Australian Supported Learning Program (ASLP), modelled on the SLP (Booth & Booth, 2003). The ASLP aimed to broaden social networks, strengthen community participation and reduce psychological distress for mothers with intellectual disability. Thirty two mothers completed the 10-week program. Prior to the program, mothers identified individual goals and program goals related to community participation. At this time, the mothers were assessed as having low levels of psychological wellbeing and high levels of depression, anxiety and stress compared to population norms. They had little confidence in their ability to achieve their goals and perceived outside interference from obstacles beyond their control. Program participation produced positive effects on psychological wellbeing and social relationships. For example, mothers gained confidence in accessing community activities and in knowledge of available community resources. Four out of five mothers partially or fully achieved their personal goals and over 90% achieved all 10 program goals.

---

[2] The results of the study were first reported in McConnell, Dalziel, Llewellyn, Laidlaw & Hindmarsh (2009). As the findings relate to the same study, the earlier publication was excluded from the review.

2.3.4.   *A study about community participation*

Llewellyn and Gustavsson (2010) examined the agency of parents with intellectual disability in creating social relationships in their communities. The study involved in-depth interviews with four mothers and one father with intellectual disability who were known to the researchers. One mother was recently separated from her partner, who was also a participant in the study, two mothers were single parents and one was married. The study used a semi-structured interview guide to explore the daily routines of parents and the meaning that everyday activities held for them. The authors found that the routines of everyday life as a parent provided opportunities to engage in the community and a sense of belonging to community-based groups. For example, through their children's participation in school and social activities, parents gained opportunities to meet other parents. Social activities and everyday family routines created a sense of belonging to a broader community of parents. These findings indicate that parents capitalised on their physical presence in their local neighbourhoods to foster community connections. Being a parent granted them membership of the socially esteemed group and created community belonging.

2.3.5.   *Findings about the social context of mothers with ID*

The findings of the studies reviewed above indicate that the social context of some mothers with intellectual disability is more restricted than for others. Social restrictions appear to relate to the characteristics of mothers' social networks. Typically, mothers with intellectual disability appear to have small social networks composed of family members or formal services (Llewellyn et al*.,* 1998; Llewellyn & McConnell, 2002, 2004; Stenfert-Kroese et al*.*, 2002). Several studies noted the absence of friends or neighbours in the support networks of mothers with intellectual disability (Llewellyn, 1995; Llewellyn et al*.,* 1998; Llewellyn & McConnell, 2002;

Stenfert-Kroese et al., 2002). A number of studies found that some mothers with intellectual disability felt dissatisfied with their level of community participation (Ehlers-Flint, 2002; Feldman et al., 2002; Llewellyn & McConnell, 2002; Llewellyn et al., 1998). However, a restricted social context appeared to relate less to network size and more to the quality of the social support and the longevity of the social relationships (Feldman et al., 2002; Llewellyn, 1995; Llewellyn & McConnell, 2004; Stenfert-Kroese et al., 2002).

Mothers whose support networks promoted their parenting competence (Tucker & Johnson, 1989) and who had long-term relationships with supportive family members or partners (Llewellyn & McConnell, 2002, 2004; Stenfert-Kroese et al., 2002) were more likely to be satisfied with their social support, although some were dissatisfied with their social networks. For example, family members might be perceived as critical of their parenting (Ehlers-Flint, 2002; Llewellyn et al., 2002; Stenfert-Kroese et al., 2002; Tucker & Johnson, 1989) or the level of support available to them viewed as inadequate (Feldman et al., 2002). Mothers with supportive families appeared to view formal services with greater wariness than more isolated mothers (Llewellyn & McConnell, 2002, 2004; Traustadóttir & Sigurjónsdóttir, 2008). New mothers (Llewellyn, 1995) and those who lived alone (Llewellyn & McConnell, 2002, 2004) or lacked supportive families (Ehlers-Flint, 2002) may have seen formal services in a more positive light. Social support viewed by mothers with intellectual disability as unreliable, judgmental or inappropriate could impact negatively on their psychological wellbeing (Feldman et al., 2002; Stenfert-Kroese et al., 2002). Satisfaction with support was found to be associated with positive mother–child interactions (Feldman et al., 2002).

The social context of mothers with intellectual disability appears to be influenced by their living arrangements. Thirteen studies noted the relationship status of mothers and, in 10 studies, the majority of mothers had partners (see Table 2). Overall, it appears that living with a partner or another adult family member can provide crucial support for mothers with intellectual disability (Llewellyn & McConnell, 2002, 2004). In contrast, the circumstances for single mothers who lacked informal support appeared to be particularly socially restricted. The social relationships of single mothers in these circumstances were found to be less enduring and reliable (Llewellyn & McConnell, 2002, 2004). Depending solely on support from formal services may put them at increased risk of social isolation because of the typically short-term nature of formal services (Llewellyn & McConnell, 2004).

Some mothers with intellectual disability see themselves as lacking opportunities to form friendships and participate in their community (Ehlers-Flint, 2002; Llewellyn, 1995; Llewellyn et al., 1998). Others may take advantage of everyday parenting activities, such as taking their child to a park, school or social group, to foster connections with other parents (Llewellyn & Gustavsson, 2010). It has been suggested that mothers with intellectual disability are likely to lack peer support from other mothers with intellectual disability (Llewellyn, 1995; Llewellyn et al., 1998). Programs to improve the social skills of mothers with intellectual disability were found to be effective for building the confidence they needed to participate in community life (Booth & Booth, 2003; McConnell et al, 2010; McGaw et al., 2002). These programs also offered participants opportunities to meet other mothers with intellectual disability. Program evaluations noted that mothers viewed this positively.

2.3.6.   *Studies about mothers' social context and child outcomes*

Four studies have investigated whether a relationship, exists between two aspects of mothers' social context and child outcomes. The first aspect examined has been maternal social support and the quality of children's home environment and the second the home environment and academic or behavioural outcomes.

The first study reviewed is an unpublished doctoral dissertation by Wise (1997), in which she conducted a secondary analysis of data collected for an earlier study (Keltner, 1993). Of the four studies included in this section of the review, this is the only study which did not report child outcomes. Wise (1997) analysed the data about two aspects of mothers' social worlds: maternal social support and quality of the home environment. Fifty low-income mothers with intellectual disability and a matched comparison group of 50 mothers of average intelligence took part in the original study (Keltner, 1993). Mothers had been recruited through prenatal clinics, hospital or perinatal units and emergency rooms. One in four lived in poverty and three in four were single mothers. Wise (1997) reported that the home environments of most mothers in both groups offered at least moderate physical and emotional stimulation for children. However, the homes of mothers with intellectual disability were more likely than those of comparison group mothers to offer a lower level of stimulation.

Higher maternal intellectual ability and living in less violent neighbourhoods significantly and positively predicted the quality of the home environment for mothers with intellectual disability. Single mothers who lived with brothers perceived themselves as having more social support than single mothers living alone or with female or older male relatives. It is possible that living with a younger male relative may have provided single mothers with practical assistance and protection from the

perceived dangers of high-risk neighbourhoods. However, if a brother's children also shared the household, the children of a mother with intellectual disability were likely to have a less stimulating home environment. The author suggested that these homes might have had fewer resources and been more overcrowded, limiting the learning opportunities available to children.

Three studies have examined an association between a specific aspect of mothers' social context and child outcomes. In the first of these, Feldman and Walton Allen (1997), examined the association between poverty and child outcomes in middle childhood for children of mothers with intellectual disability. The study included 27 mothers with intellectual disability from similar low socioeconomic backgrounds and a matched comparison group of 25 mothers with average intelligence. Mothers with intellectual disability were recruited through formal services and control group mothers through community advertisements. The quality of the home environment and mother-child interactions, child IQ and behaviour problems were measured. Socioeconomic status did not explain the association between poorer academic and behavioural outcomes for children of mothers with intellectual disability. While social support was not a primary research focus, the study found that mothers with intellectual disability reported significantly higher rates of social isolation than the comparison group. A significant positive association was found between maternal social isolation and a less stimulating home environment, child conduct problems and hyperactivity disorders. The results suggest possible social difficulties for school-aged children, particularly boys, who have socially isolated mothers with intellectual disability.

Aunos, Feldman, and Goupil (2008) examined the relationship between parenting stress for 32 mothers with intellectual disability and behavioural outcomes for their children aged from 2 to 13 years. The aspects of mothers' social context examined in this study were social support, maternal stress and the home environment. The majority of children were found not to have significant behavioural problems, with only six children (19%) assessed as having problems at the clinical level. The authors found that parenting stress was significantly and directly associated with child behaviour problems, but a hypothesised mediating role of parenting practices was not supported. The research design did not permit direction of effect inferences to be made. Despite consistency between maternal reports and worker ratings of child behaviour, the authors noted two other possible explanations for an association between child behaviour problems and parenting stress. First, stressed mothers might have viewed their child's behaviour more harshly; second, a reciprocal relationship between parenting stress and child behaviour problems might exist. Behaviour problems were more common among the school-aged children and the home environments for children in this age group were less stimulating.

Aunos and colleagues (2008) found an association between support network size and the quality of the home environment. Social support was typically provided by family, followed by formal services. Almost three quarters of the mothers received regular support. However, over half (53%) of the mothers reported borderline or clinically significant levels of parenting stress. Elevated stress may indicate that the social support available to these mothers did not meet their needs. Unlike the earlier study by Feldman and Walton Allen (1997), no gender differences in maternal reports of problem behaviours were found for school-aged children of mothers with intellectual disability.

More recently, Wade, Llewellyn and Matthews (2011) examined the effect of contextual factors on parenting practices and child wellbeing for parents with intellectual disability and their children. The contextual variables examined were social support, socioeconomic status and parental mental health. The results were based on data collected about 120 parents, 112 being mothers, and one of their children aged younger than 6 years of age. Parents were participants in a specialist parent training intervention. Community level features such as social support and socioeconomic status were assessed, as well as parent and child features, parent health and parenting practices, and child development and health.

The study established a relationship between the parenting practices of mothers with intellectual disability and child wellbeing. The relationship was mediated by the influence of environmental factors such as socioeconomic status and social support. Social support indirectly exerted an influence on parenting by its impact on maternal mental health. The direct influence of social support on parenting practices was exerted through the influence of social support on parental efficacy about parenting tasks. Distal environmental factors such as neighbourhood disadvantage influenced child wellbeing through the proximal impact of parental mental health on parenting practices. However, the indirect effect of neighbourhood disadvantage on parenting was found to be minimal once access to social support was taken into account.

2.3.7. *Summary of findings about a relationship between mothers' social context and child outcomes*

Findings from the four studies that examined a relationship between at least one aspect of mothers' social context and outcomes for their children suggest that there are factors that may hamper effective parenting by mothers with intellectual disability. Social support was found to exert an influence on children in several ways. First, it

influenced maternal mental health and this impacted on parenting practices and, thereby, child wellbeing (Wade et al., 2011). Second, social support influenced the quality of the home environment that mothers with intellectual disability provided for their children. Findings suggest that mothers who lacked adequate social support (Aunos et al., 2008) or lived in high-risk neighbourhoods (Wise, 1997) may provide a less stimulating learning environment for their children. Third, social isolation was found to increase maternal stress for mothers with intellectual disability. This was associated with increased behavioural problems, or accentuated mothers' perceptions of behaviour problems, in their school-aged children (Aunos et al, 2008). Since behaviour problems can contribute to social difficulties at school, social isolation of mothers with intellectual disability may influence a key aspect of their children's social worlds in middle childhood.

Along with social support, three studies examined socioeconomic status or neighbourhood disadvantage as distal environmental factors that influenced developmental outcomes for children of mothers with intellectual disability (Feldman & Walton Allen, 1997; Wade et al., 2011; Wise, 1997). In two studies it was found that socioeconomic status and neighbourhood disadvantage indirectly influenced child outcomes, with the relationship mediated by social support (Wade et al., 2011; Wise, 1997). For example, perceived neighbourhood safety risks may have shaped the support needs of mothers with intellectual disability. In such circumstances, the protective role of social support may have taken priority over its contribution to a positive home learning environment for children (Wise, 1997).

The findings from the 17 studies suggest that for some mothers with intellectual disability, their social context is restricted. In particular, mothers who lack support

from their family members or partners are more likely to be socially isolated (Llewellyn & McConnell, 2002, 2004). The support they receive from formal services is likely to be less enduring than that provided by extended family and partners (Llewellyn & McConnell, 2004). However, support network size does not necessarily equate to support satisfaction. Family support that is viewed as judgmental (Stenfert-Kroese et al., 2002) or that does not match a mother's perceptions of her support needs (Aunos *et al.,* 2008; Feldman et al., 2002) can increase the risk of maternal stress. Maternal stress has been found to influence the parenting of mothers with intellectual disability (Feldman et al., 2002).

Social support for mothers with intellectual disability has been associated with the quality of the home environment for their children. Social support influences parenting efficacy on child care tasks (Wade et al., 2011). Inadequate or inappropriate support for mothers may contribute to a less stimulating home learning environment for their school-aged children (Aunos et al., 2002; Feldman & Walton Allen, 1997). The support needed by mothers with intellectual disability living in disadvantaged, violent neighbourhoods may limit their ability to create a stimulating home environment for their children (Wise, 1997). The question of the impact of the home environment on developmental outcomes for these children has received attention in three studies (Aunos et al., 2008; Feldman & Walton Allen, 1997; Wade et al. 2011). Two studies indicated that, although serious behavioural problems were not typical, school-aged children whose mothers with intellectual disability are stressed or socially isolated may face an increased risk of behavioural problems (Aunos et al, 2008; Feldman & Walton Allen, 1997). In one study, boys were found to be at higher risk of behavioural problems than girls (Feldman & Walton Allen, 1997). However, the strength of findings about behavioural outcomes is constrained by the paucity of

studies investigating this topic. Parenting efficacy and the warmth demonstrated by mothers with intellectual disability has been associated with positive emotional and behavioural outcomes for their younger children (Wade et al., 2011). However, the relationship between parenting by mothers with intellectual disability and child behaviour needs to be examined using a design that permits inferences to be made about the direction of effect between maternal stress and child behaviour problems. The investigation of cognitive and academic outcomes in middle childhood for children of mothers with intellectual disability is limited. One study used a design that permitted comparison with children from similar backgrounds whose mothers had no intellectual disability (Feldman & Walton Allen, 1997). The findings suggested that deficiencies in the home environment may be associated with lower IQ and academic problems for the school-aged children of mothers with intellectual disability.

2.4.   **Limitations**

The first limitation in the research about the relationship between mothers' social context and child outcomes is that the focus has been restricted to the home environment with experiences away from home, for example community participation and leisure activities comparatively neglected

The second limitation concerns the range of contextual influences that have been the focus of the literature. To date, research about the social contexts of mothers with intellectual disability has focused on their support networks and social support, social skills, social relationships and community participation. More than half (9) of the studies reviewed reported the socioeconomic status of participants (Aunos et al., 2008; Ehlers-Flint, 2002; Feldman et al., 2002; Feldman & Walton-Allen, 1997; Llewellyn & McConnell, 2002; McGaw et al., 2003; Stenfert-Kroese et al., 2002; Wade, 2010;

Wise, 1997). In all these studies, the majority of participants were from lower socioeconomic or highly deprived backgrounds (see Table 2). However, only three studies (Feldman & Walton Allen, 1997; Wade et al., 2011; Wise, 1997) investigated the influence of socioeconomic and neighbourhood disadvantage on the social context for mothers with intellectual disability. It is possible that unexplored distal influences such as socioeconomic status and neighbourhood disadvantage explain the restricted social context reported in some studies. Similarly, other contextual factors may have contributed to social restrictions. For example, one descriptive study (Ehlers-Flint, 2002) noted the possible influence of a history of childhood abuse or adult partner violence on social support for mothers with intellectual disability. Investigation of the influence of factors such as partner violence or past abuse on maternal social support would build on current knowledge, particularly the robust evidence from a recent study (Wade et al., 2011) demonstrating an association between maternal social support, parenting practices and child outcomes.

The third limitation relates to the sampling method used to recruit participants. In all but one study (Wise, 1997) a convenience method was used. In 13 studies, this method involved recruiting mothers who used formal services (see Table 2). Mothers who took part in the remaining three studies (Llewellyn & Gustavsson, 2010; Traustadóttir & Sigurjónsdóttir, 2008; Tucker & Johnson, 1989) were known to researchers through previous research participation. From available information, it appears that their initial contact with researchers was through formal services. Therefore, 16 studies involved mothers who currently or previously received support from a formal service. It is possible that mothers who use formal services have higher support needs than others, and this introduces a potential sampling bias in the studies.

This may lead to an overestimation of the risk of social isolation or parenting stress for mothers with intellectual disability.

The fourth limitation concerns the types of study included in the review. The majority of studies in the literature are small, descriptive or exploratory studies (see Table 2). They describe or explore specific but limited characteristics of the social context of mothers with intellectual disability at one point in time. Comparing findings across these studies makes it possible to identify common themes that have been identified in the literature. For example, several studies (Ehlers-Flint, 2002; Feldman et al*.,* 2002; Llewellyn & McConnell, 2002, 2004; Stenfert-Kroese et al*.,* 2002) identified a potentially restricted social context among mothers who lack access to responsive, reliable and appropriate social support that addresses their identified needs. However, aggregated findings from studies using these research designs must be interpreted cautiously. Only five studies (Aunos et al*.,* 2008; Feldman & Walton Allen, 1997; Feldman et al., 2002; Wade et al*.,* 2001; Wise, 1997) investigated the association between contextual influences of mothers with intellectual disability and either their parenting practices or child outcomes. Only one study (Wade et al., 2011) employed a research design that permitted statistical analysis of proximal and remote contextual influences for mothers on their children and developed a theoretical model, informed by ecological theory (Bronfenbrenner, 1979) to explain different contextual influences.

2.5. **Conclusion**

The review of studies examining the social context of mothers with intellectual disability or an association between a mother's social context and child outcomes permits several conclusions. First, differences in household composition appear to

differentiate the social networks of mothers with intellectual disability. Second, some mothers with intellectual disability face social restrictions that may negatively impact on their parenting. Reliable, enduring and confidence-promoting social support positively influences the parenting practices of mothers with intellectual disability. A small group of studies has investigated the association between social support, parenting practices and child development (Aunos et al., 2008; Feldman & Walton Allen, 1997; Wade et al., 2011; Wise, 1997). A third conclusion, based on findings from those studies, is that social support for mothers can influence developmental outcomes for their children. This finding is strengthened by the robust research design employed in one study (Wade et al., 2011). The findings from two studies (Aunos et al, .2008; Feldman & Walton Allen, 1997) suggest a possible association between social isolation and parenting stress in mothers with intellectual disability and behavioural problems in their school-aged children. The influence of a mothers' social context on the social worlds of her child, particularly in middle childhood, has received limited research attention.

This review makes a useful contribution to the current study by confirming that differences exist in the social contexts of mothers with intellectual disability, in terms of their access to reliable, timely and responsive social support. This aspect of mothers' social context has been found to impact on their mental health, their parenting practices and the home environment they create for their children. The limited findings available about the relationship between these aspects of the social context of mothers and the lives of their children suggest that parenting stress and social isolation may impact on the quality of the home learning environment. Notwithstanding this contribution, our understanding about the social worlds of these children in middle childhood remains minimal. In the next chapter, studies of the life

experiences or developmental outcomes for children of parents with intellectual

disability are reviewed. The literature is discussed in terms of its contribution to

understanding the social worlds of this group of children, particularly in middle

childhood.

CHAPTER 3: STUDIES ABOUT CHILDREN OF PARENTS WITH INTELLECTUAL DISABILITY

3.1.   **Introduction**

This chapter presents an abstract and a table from a literature review which was published as part of the doctoral process in a peer-reviewed scientific journal (Collings & Llewellyn, 2012). The full text of this publication can be found by following the link:

http://informahealthcare.com.ezproxy2.library.usyd.edu.au/loi/doi/abs/10.3109/13668 250.2011.648610.

The complete thesis is available from the Research Papers and Publications Collection at the Faculty of Health Science, University of Sydney, and can be found by following the link: http://hdl.handle.net/2123/11906.

The review of studies between 1983 and 2011 was conducted to examine the state of knowledge about outcomes for children of parents with intellectual disability. A study that was published after the review was completed (O'Neill, 2011) is included in this chapter to bring the review up to date.

The published review was conducted with a broader aim than that which guides the study reported in this thesis. The aim of the review was to understand the state of knowledge about this group of children. It therefore included all studies about children of parents with intellectual disability published during the time period and was not limited only to those about children's social worlds. The focus in relation to parents was also broader and not limited to mothers as is the case in this thesis.

3.2.   **Abstract**

Background: Children of parents with intellectual disability are assumed to be at risk of poor outcomes but a comprehensive review of the literature has not previously been undertaken.

Method: A database and reference search from March 2010 to March 2011 resulted in 26 studies for review.

Results: Two groups of studies were identified. The first investigated an association between parental intellectual disability and child outcomes where there was significant disadvantage. Some findings suggest low parental intellectual capacity can negatively impact child outcomes but others indicate child development approaches population norms. A second, small group of studies explored narrative accounts of childhood to find that social exclusion, bullying and stigma are commonplace. Removal from parental care emerged as a significant risk for this group of children.

Conclusions: Studies focusing on child development represent 85% of the literature but reach no consensus about likely developmental or behavioural outcomes. Children studied usually come from clinical populations or other high risk groups, and are typically young children.

Keywords: child outcomes, parental intellectual disability, child development

Table 1. Studies about children of parents with Intellectual disability (ID)

Year	Author	N	Focus[a]	Age	Sample	Design	Purpose	Measures	Label used[b]	Mother features	Child features
1983	Gillberg & Geijer-Karlsson	40	Yes	1–21 years	Clinical (disability services)	Medical and psychiatric records review	Examine outcomes for children of mothers with ID	Nil	Mental retardation	Low IQ, low SES, childhood deprivation, high proportion single mothers	35% ID; 85% social and behaviour problems
1984	Ramey & Campbell	111	No	Newborn	Community (prenatal clinic and clinical (social services)	Randomised control trial (5 years)	To determine if educational day care improves IQ and academic outcomes for children at risk of educational disadvantage	Bayley Scales of Infant Development; Stanford-Binet Intelligence Scale; McCarthy Scales	Mental retardation	"High risk" = young, African American, single parent, extreme poverty, low educational attainment, overcrowded housing	Healthy and free from diagnosed disabilities
1985	O'Neill	19	Yes	Unknown	Community (school)	Cross-sectional	Determinants of behavioural and emotional adjustment for children of mothers with ID	Rorschach & Thematic Apperception Test; interviews; school records	Mental retardation	Low IQ, high proportion single mothers	Normal range IQ
1986	Seagull & Scheurer	64	Yes	Unknown	Clinical (child welfare services)	Child protection records review	Review placement outcomes for children of mothers with ID who were neglected/ abused	Nil	Mental retardation	Low IQ, low SES, 75% childhood deprivation/abuse, couple status unknown	Unknown
1988	Garber	40	No	Newborn	Community (infant health clinics)	Intervention (alternate assignment) (5 years)	Improve academic performance/ prevent learning difficulties	Gesell Schedules; WISC IQ; Stanford Binet	Mental retardation	Maternal IQ < 75, low SES, African American, high proportion single mothers	Study group: 9 boys, 11 girls; healthy, no gross pathologies detected
1989	Nichols	4	Yes	8–9 years	Clinical (social services)	Case studies	Assess self-esteem of children of mothers with ID	Roberts Apperception Test; Piers–Harris Self-Concept Scale; Coopersmith Self-Esteem Inventory	Mental retardation	Low IQ	Normal range IQ; 2 girls, 2 boys

(Continued)

Table 1. (Continued)

Year	Author	N	Focus[a]	Age	Sample	Design	Purpose	Measure	Label used[b]	Mother features	Child features
1991	Taylor et al.	206	Yes	4 years (mean)	Child protection	Court records review	Prevalence of parental low IQ/ mental illness in maltreatment cases	Questionnaire to determine level of risk	Intellectual impairments	84% psychiatric disorders; high proportion (76%) single mothers	67% from "minority" backgrounds
1993	Feldman et al.	28	No	5 months–2 years	Clinical (social and health services)	Randomised control trial (48 weeks)	Improve language development by improving mother–child interactions	Bayley Scales (plus observation)	Mental retardation	Caucasian, low SES; couple status unknown	16 boys, 12 girls; 30% with developmental delay; no disabilities
1995	Keltner et al.	40	No	1–3 years	Health clinics and child protection agencies	Randomised control trial (1 year)	Improve mother– child interactions	Slosson Intelligence Test – Revised; Nursing Child Assessment Teaching Scale	Intellectual limitations	IQ < 85 (mean 59); 60% African American; low SES; > 50% single parents	At risk of developmental delay
1996	Bowling & Keltner	62	Yes	2 years	Community (infant health clinic)	Medical records review	Examine differences in child health indicators of children of mothers with and without ID	Bayley Scales	Intellectual limitations	Maternal IQ < 70, most single mothers and African American	43% of the children with mothers with ID had IQ < 70; more likely to be delayed in speech and socialisation
1997	Ronai	1	Yes	Adult	N/A	Autobiography	Account of childhood with a mother with ID		Mental retardation	Mother with ID, estranged from husband	Unknown
1997	Feldman & Walton-Allen	52	Yes	6–12 years	Clinical (disability services)	Concurrent correlation	Examine relationship between poverty, maternal IQ, and child outcomes	HOME child behaviour checklist; WISC-R & WRAT-R	Mental retardation	Maternal IQ < 70, low SES; Caucasian, high proportion single mothers	No known disabilities; mother with ID: 19 boys, 8 girls; comparison: 12 boys, 13 girls
1997	March et al.	65	Yes	1–17 years	Population (national survey)	Medical records	Determine prevalence of parents with ID; examine child outcomes	Einstein Parent Screening Instrument; child developmental profile	Mental retardation	Maternal IQ < 70; 49 single mothers and 16 couples with ID	43% learning or developmental issues; 39% removed from parental care

63

Year	Author	N		Age	Recruitment	Design	Aim	Measures	Disability	Sample	Findings
1998/ 2000a	Booth & Booth	30	Yes	Adult	Clinical (social services)	Narrative case studies	Lives of adult children with parents with ID	N/A	Learning difficulties	26 mothers with ID; 4 fathers with ID, all low SES, 9 couples and 7 deceased parents	16 men, 14 women; 50% learning disabilities
1999	Glaun & Brown	17	No	5 months–6 years	Child protection	Court records review	Compare parent and child factors in child protection cases with mothers with ID	Nil	Intellectual disabilities	Maternal IQ <70; 11 Caucasian, 1 Maori; 75% history of sexual abuse and deprivation; 2/3 isolated, 1/3 homeless	59% developmental problems including 29% developmental delay; 18% physical ill-health
1999	Keltner et al.	70	Yes	2 years	Community (antenatal)	Concurrent correlation	Compare impact of maternal IQ and poverty on child development	Sosson IQ Test; Vineland Adaptive Behavior; Bayley Scales	Intellectual limitations	Most young, low SES, African American, single mothers	High % of children of mothers with ID—cerebral palsy & developmental delay compared to other group
2002	Perkins et al.	36	Yes	9–17 years	Clinical (disability services)	Cross-sectional	Examine effect of maternal style and ID stigma on child self-esteem, identity	Multiple measures of self-esteem and attachment	Developmental disabilities	Mother with ID, low SES	18 boys, 18 girls. No ID or behaviour problems
2003	Llewellyn et al.	469	No	5 years (mean)	Child protection	Court files	Prevalence of parents with disabilities in court proceedings		Intellectual disabilities	53% single mothers with ID; no single fathers with ID	Unknown
2003	McConnell et al.	37	Yes	<5 years	Clinical (social services)	Concurrent correlations	Relationship between child development and maternal/home variables	Developmental Profile II; Kaufman; Neale Analysis; SF-36; HOME	Intellectual disability	45 parents with ID including 40 mothers (23 with partners) and 5 fathers; English speaking, low SES	20 girls, 17 boys; high incidence of organic pathology
2005	Traustadóttir & Sigurjónsdóttir	3	Yes	Adult	Convenience (known to researchers)	Narrative case studies	Life history of adult children of mothers with ID	N/A	Intellectual disabilities	Low IQ, 2 sexually assaulted; institutionalised; all fathers unknown	2 grew up in rural areas; 1 woman with ID

(Continued)

Table 1. (Continued)

Year	Author	N	Focus[a]	Age	Sample	Design	Purpose	Measure	Label used[b]	Mother features	Child features
2005	Booth et al.	828	No	<1 month–16 years	Child protection	Court records review	Prevalence of parents with ID in court proceedings	N/A	Learning difficulties	59 mothers and 21 fathers with ID (14 couples)	Most with an English background, 1:3 impairment/disability
2007	McGaw et al.	58	No	5–17 years	Clinical (disability services)	Concurrent correlations	Effect of childhood trauma/psychopathology of parent with ID on child behaviour, mental health	Parent Assessment Manual; Childhood Trauma Questionnaire; Psychiatric Assessment Schedule; Devereux Scale	Intellectual disabilities	Low IQ, low SES; 50% partners with history of violence/prison, 19 parent couples, 10 single mothers	31 boys, 27 girls, 12 with learning difficulties
2007	Cleaver & Nicholson	228	No	<17 years	Clinical (social services)	Case records	Effectiveness of social service interventions for parents with ID	Nil	Learning disabilities	76 with ID: more likely to be disadvantaged than comparison group. Both groups: +80% mother = primary carer	Similar % of boys and girls, 23 children with developmental disability; 12 chronic illness
2008	McConnell et al.	57	Yes	Newborn	Community (antenatal)	Medical records	Prevalence of adverse birth outcomes	Nil	Intellectual disabilities and learning difficulties	Mothers with ID (and comparison group)	Higher rates of low birth weight, admissions to ICU, special care nursery
2008	Aunos et al.	32	No	2–13 years	Clinical (disability services)	Concurrent correlations	Maternal social support, health/wellbeing on child behaviour	SF-36; Parenting Stress Index; HOME; child behaviour checklist	Intellectual disabilities	Low SES, no other characteristics known	Good health, 2 with developmental disability, 16 boys, 16 girls
2010	Faureholm	23	Yes	8–22 years	Clinical—known to disability services	Narrative case studies	Childhoods of children with mothers with ID	N/A	Intellectual disabilities	Mothers with ID, no other characteristics known	11 boys, 12 girls, 7 with mild ID

Note. [a]Focus of research was primarily the children of parents with intellectual disabilities (not their parents or a different child group). [b]To describe parental intellectual disability. [c]Both and Booth (1998) and (2000) report on the same study.

3.3. Study published after Collings and Llewellyn (2012)

Twenty years after publication of a study about the behavioural adjustment of 23[3]

children of average or above average intelligence with parents with intellectual

disability (O'Neill, 1985, included in the previously published review article), O'Neill

(2011) conducted a follow-up study to investigate their patterns of adult adjustment.

Twenty participants of the original study in 1985 were located and 17 took part in

semi-structured interviews. Two others consented to participate on the basis of

information obtained from other sources and a third, who had died seven years after

the first study, was also included based on field notes from other sources (N=20).

Semi-structured interviews addressed current life situation, changes since the previous

study, life events and perception of family-of-origin. Information about legal issues,

substance abuse or family problems, socioeconomic status and mental health was

obtained and analysed to determine patterns of adjustment. Three patterns were

identified. These were serious adjustment problems, taking the parent's role in the

family of origin, and normal adjustment.

Sixteen adults were found to be normally adjusted and four had serious adjustment

problems. This was in contrast to the patterns observed in childhood where only five

children were found to be normally adjusted. All three of the children identified as

rebellious in childhood were well-adjusted adults and the two children who had

appeared to imitate their parent with intellectual disability continued to have some

---

[3] O'Neill (1985) identified 23 children of parents with intellectual disability whose IQ was average or

above but four were subsequently excluded from further analysis because they were not currently living

with their parent with intellectual disability. Therefore, results for 19 children were included in the

published review.

adjustment difficulties in adulthood. Changes to socioeconomic status were identified. During childhood the participants were described as "underclass" or disadvantaged but most adults were described as being working class and two were described as upper middle class. Four had graduated from high school and several others had found alternative pathways to further education. In total, nine had gained post-secondary education. Compared to population norms, there was a higher incidence of depression and drug disorders but more than half the adults were currently diagnosis-free and four had never been diagnosed with any mental health condition. There was substantial between-group variation in childhood living arrangements. Only seven children (35%) had lived with their parent with intellectual disability throughout childhood. Two had moved in with a parent without intellectual disability and 11 had less stable home environments, which included moving between parents and foster care, psychiatric hospital and treatment centres. Six eventually found permanent foster homes and five left home in adolescence.

In O'Neill's study, seventeen adults reflected in interviews on childhood and the parenting they had received. Five gave entirely negative accounts and mentioned neglect, inadequate home environments or physical, verbal or psychological abuse. Twelve adults reported an appreciation of the difficulties their parents had faced and referred to parental loyalty and self-sacrifice. They reflected on contextual factors in their parents' own childhoods that influenced their parenting, such as mistreatment, deprivation, and the absence of educational and other opportunities, some of which arose from stigma and social exclusion associated with intellectual disability. Seven adults described their parent with intellectual disability as self-absorbed and reported that this had hampered effective parenting. However, an ongoing sense of responsibility and connection by the adult children to this parent was demonstrated.

Eight parents were currently being supported by their adult children, including six of those who were described as having provided inadequate parenting during childhood. The ongoing connection to parents was especially notable in light of the high rate of separation from mothers during childhood or adolescence.

The study contributes to the literature by demonstrating that developmental risks identified in childhood do not necessarily result in long-term adjustment problems. Although O'Neill reported that the rate of positive adjustment for the group as a whole was higher in adulthood than in childhood, the study did not report adult outcomes directly associated with individual children. Therefore, it is not possible to determine the extent to which intra-group differences in childhood and adolescence are reflected in adult outcomes. One aspect of interest which not further examined is that more than half (55%) of the children were separated from their parent with intellectual disability, but no comparison of adult circumstances based on childhood removal status was undertaken. Given that the risk of child removal has been noted to be disproportionately high for this group of children and that no studies to date have examined the impact, this represents a missed opportunity.

3.4.   **Chapter summary**

This chapter includes a published review of studies that addressed the developmental outcomes and, to a lesser extent, life experiences of children of parents with intellectual disability. The findings from this review provide some insights into the social worlds of children of mothers with intellectual disability.

First, from this body of research, it is clear that children of parents with intellectual disability live in a social context that has been considered by researchers as being "at risk". This representation can itself increase their risk of being removed from parental

care if they encounter child protection agencies. Second, the preoccupation with examination of the risk of developmental difficulties or neglect and abuse has meant that other aspects of these children's lives such as their social worlds have been under-explored, with only one study, that by Faureholm (2010), specifically concerned with presenting childhood from a child's perspective.

Third, researchers have focused on early childhood. There are two important implications of this for understanding the social worlds of children in middle childhood. The first is that research on early childhood typically considers children as recipients, not agents in their own lives. Thus, influences such as socioeconomic status, substance abuse, mental illness and social isolation are all considered to impact on the child, with little or no consideration of the child's potential for reciprocal influence or interaction. . The second implication of a focus on early childhood is that, given the close association between mother and child at that development stage, influences beyond the home that become critical in middle childhood are not investigated. To date, research about children of parents with intellectual disability has concentrated on mothers and the home environment. Children of mothers with intellectual disability encounter many new social contexts in middle childhood, such as schools and peers, and these exert a growing influence on their social worlds that need to be explored.

In the study reported in this thesis I argue that to appreciate the influences that shape childhood for these children we need to understand their social worlds in middle childhood from their own perspective. The next chapter provides the theoretical basis for a study that sees children as agents who actively shape their social worlds in middle childhood.

CHAPTER 4: GUIDING THEORIES

4.1.   **Introduction**

This chapter describes two instrumental theoretical frameworks that guided the approach taken to the research question that drives the study, namely, what are the influences in the social worlds of children of mothers with intellectual disability in middle childhood? The first theoretical framework that informed my approach recognises the agency of children in their social worlds and the value of hearing their perspective on things that matter to them. The second theoretical framework argues that the relationship between children and their social environments is bidirectional, with children actively shaping their social worlds, and being influenced by, their social interactions. Before outlining the first theoretical framework that influenced the thesis, the sociology of childhood, it is necessary to explain the contribution post structuralism made to the development of this theory.

4.2.   **Post-structuralism**

Post-structuralism drove a fundamental epistemological shift in academia through its critique of the Enlightenment ideals of objectivity, universality and truth. The critique has its origins in mid-twentieth century structuralist theory, which explained that human culture could be understood as a structure based on language and governed by a series of hierarchical binary opposites, such man/woman, conscious/unconscious, public/private (Castaneda, 2002). By the 1970s, post-structuralism had emerged to critique structuralism and, in so doing, to extend the structuralist interrogation of language. This included a critique of the relationship between signs and signifiers, through which meaning is not only conveyed but constructed (Denzin & Lincoln, 2000). The theory departed radically from structuralism by rejecting the view that one

70

term in a binary pair was innately dominant. The process of deconstructing the meaning of each category, and the knowledge systems responsible for constructing these meanings, would expose the dominant term as dependent on its subservient partner (Castaneda, 2002).

Post-structuralist theory critiques the "universal", or normative, subject as being "Western", heterosexual, able-bodied, and male (Castaneda, 2002). It exposes the debt this universal subject owes to the unacknowledged "other" who, by virtue of gender, class, race and so on, is represented in terms of what it is not. An implication of this insight is that the "universal" subject cannot be assumed to speak for all. Thus it is necessary to hear the voices of those from marginalised standpoints to understand their life experiences and viewpoints. It may be presumed that post-structuralism prompted a plethora of new research designed to give voice to these previously marginalised standpoints, including children's perspectives on their lives. However, post-structuralism also heralded a crisis of legitimation in academia by rejecting the truth claims of the "grand narratives" of history, philosophy and science (Denzin & Lincoln, 2000). In the wake of this, the authority of researchers to speak for their participants or to capture their lived experience was delegitimised. Denzin and Lincoln (2000) explained this using autobiography as an example. The notion that people can reveal the truth about themselves becomes questionable if one accepts that the self is constituted in and by language and the unconscious. However, as Denzin and Lincoln (2000) added, acknowledging the social construction of reality does not necessarily deny the value of research that presents individuals' interpretations of their intentions and actions.

4.3. The sociology of childhood

Originally known as the "new" sociology of childhood (James & Prout, 1997), the theory more commonly known today as the sociology of childhood argues that childhood is represented in different ways, depending on the meaning that society holds about children in its particular context (Castaneda, 2002). The theory challenges the notion that childhood is merely a temporary state on the path towards adulthood and insists that is a life stage in its own right. Central to this theory is the conviction that children's perspectives and opinions have often been overlooked because of pervasive cultural views that represent them as innocent, immature and incapable of offering insight into their life experiences (James, Jenks & Prout, 1998). As a result, children's voices have been largely absent in public life, research and policy about issues that affect them (Prout & Hallet, 2003; Moran-Ellis & Sünker, 2013; Qvortrup, 2003).

4.3.1. *The influence of post-structuralism on the sociology of childhood*

The sociology of childhood emerged in an era of significant epistemological shifts in academia. At the centre was the transformation of the Enlightenment notion of subjectivity which was exposed as embodying a specific subject position and, by implication, denying others. This created a fertile environment for a critique of representations of childhood and the subject position of children. Alongside this was the development of a body of research, informed by social constructionism, which framed children as social actors and sought to understand their lives based on their own experiences (Hutchby & Moran-Ellis, 1998; Moran-Ellis, 2010). The significant contribution of post-structural theory to the development of the sociology of childhood was to elevate personal experience from a private concern to a subject

72

deserving of public attention. As Castaneda (2002) noted, the insight that

representations of reality are never neutral but protect existing power structures shines

the spotlight on marginalised subjectivities. In the wake of this epistemological

upheaval, research that focused on representing various minority standpoints

proliferated. According to Castaneda (2002), the sociology of childhood sought to

address the historical absence of children's self-representations by documenting

particular children's experiences of the world and analysing their social, political and

economic activity. However, some sociologists of childhood have argued that

critiques of the "universal" subject do not extend their recognition of the marginalised

"other" position to include children (Corsaro, 2011). This view is shared by Castaneda

(2002), who argued that theories of the subject continued to presume that this subject

occupied an adult standpoint. Foley, Parton, Roche and Tucker (2003) made a similar

argument by pointing out that children remain invisible in public policy because their

needs are viewed as being identical to those of their parents. Critiques such as this

have informed the evolution of the sociology of childhood and influenced the

emergence of the international movement for recognition of the human rights of

children gain momentum, embodied in the United Nations Convention on the Rights

of the Child (CRC) (UN General Assembly, 1989).

4.3.2. *The emergence of the children's rights movement*

A second influence on the sociology of childhood was the push in the 1980s to

promote formal recognition of children's human rights. In 1948, the Universal

Declaration of Human Rights (UDHR) was adopted by the United Nations (UN

General Assembly, 1948). This represents universal recognition of the basic human

rights and fundamental freedoms inherent to all human beings. Four decades later, the

United Nations responded to recognition that the unique needs of children were not

adequately addressed in the UDHR and endorsed the Convention on the Rights of the

Child (CRC) (UN General Assembly, 1989). The CRC enshrines rights for children in

54 Articles that include the right to expect freedom from various forms of exploitation

(Articles 32-36), protection from violence (Articles 6, 11, 19, 22, 38), the right to an

education (Article 28 & 29) and an adequate standard of living (Article 27), the right

to be heard in decisions that affect them (Article 12) and the right to expect that

primacy be given to their best interests in decisions affecting them (Article 3).

Some sociology of childhood researchers have claimed that the signing of the CRC

marks the introduction of a children's rights movement and a shift in thinking of

children's rights, not just as about protection from harm but also about recognition of

children's right to participate in public life and have their voices heard (e.g., Fattore,

Mason & Wilson, 2009; Foley et al., 2003; Woodhouse, 2004). Others argue that

children still lack the self-determination necessary to produce a political movement

and that children continue to be viewed as a social problem, either at risk of harm or a

disruption to adult life (Corsaro, 2011; Prout, 2003). According to Qvortrup (2005)

writing nearly a decade ago, childhood today still remains a largely private concern

and children are marginalised from the public domain. Even among those who

acknowledge that in some spheres children and young people are now given a chance

to be heard with regard to social policies that affect them, there is scepticism about

whose voices are being heard.

Writing about the social policy context in the United Kingdom a decade ago, Foley

and colleagues (2003), stated that children who are seen as posing a threat are

demonised and, in terms of the criminal justice field, subject to greater discipline and

regulation today. At the same time and also in the UK, Alan Prout (2003), an

influential contributor to the development of the sociology of childhood, cautioned that the call for children to participate more in the public realm may accentuate new social divisions between children and give rise to new power relations between children and adults. In spite of this, Prout (2003) noted that it "seems preferable, at least for the moment, to view having a voice as an improvement on being silenced or ignored" (p. 21). More recently, Moran-Ellis and Sünker (2013) have described intergenerational relationships as shaped both by an assumption that children are incompetent social actors and a politics of child rights which supports their participation in matters that affect them. The inevitable tension this creates means that children's access to participatory rights is conditional upon adult permission. It is adults who determine if, and when, children possess specific experience that equips them to speak as 'insiders' on behalf of other children. For example, those who have experienced disability, mental illness or abuse (Moran-Ellis & Sünker, 2013). These views make clear that children as a group remain unheard in their views that may run contrary to those of the adult society in which they live.

4.3.3.   *A social constructionist frame of childhood*

A significant body of work has located childhood in social constructionism, framing children as social actors whose lives can be understood through research about their personal experiences (Moran-Ellis, 2010). According to Jenks (2000), the sociology of childhood seeks to understand the images and meanings of childhood in different societies and different epochs. James (2005) makes the point that the way different life periods are defined is culturally determined. Thus, childhood and adulthood are not absolute categories and their meaning differs depending on the cultural and historical context. To quote James and Prout (1997), "the explanation of social life requires

grasping the meaning of it for participants in the context of its specific occurrence" (p. 14).

Many scholars writing from the sociology of childhood perspective credit their understanding of childhood as a social construct, a notion at the core of this theoretical perspective, to the work of French historian, Phillippe Ariès (see, e.g., Corsaro, 2011; Frønes, 2005; James, 2005; Qvortrup, 2005). Writing in the 1960s on the changing representations of children in art, Ariès provided fertile ground for the emergent sociology of childhood a decade later. According to Corsaro (2011), Ariès showed that medieval art represented children as small adults, at a time when children entered adult society as soon as they were old enough to survive without their mothers. In this largely agrarian society, children occupied public space and engaged in productive work alongside adults. The life phase known as childhood, as we know it today, did not exist. As Qvortrup (2005) pointed out, "it is one of the paradoxes of Ariès' work that children were much more visible when childhood did not exist" (p. 3).

Corsaro (2011) noted that Ariès dated the earliest recognition of children as a distinct social group at around the sixteenth century, at which time they became idealised in art as innocent. Two centuries later, depictions of children show them as immature and incompetent, needing the protection and guidance of adults to remain safe and achieve their potential. This coincides not only with the shift to industrialisation, which resulted in changes to the nature of work and increased competition for jobs, but with the birth of psychology and its focus on child development (Corsaro, 2011). In the twentieth century, at least in Western societies, school replaced work as the main site of children's productivity (Prout, 2003). According to Prout (2003), the introduction of compulsory schooling supports the view, still firmly held today, that

children represent a future investment that can be realised through education. According to Prout and Hallet (2003), school and children's formal exclusion from the workplace marks an ever-increasing tendency for children to spend time in a series of designated settings in which they come under adult supervision. Prout (2003) made the point that, with the introduction of compulsory pre-school and the period of formal schooling extended, there has been a steady increase in the length of time children spend at school. Corsaro (2011) agreed that more of children's time than ever before is now spent engaged in structured activities.

Sociology of childhood researchers have argued that contemporary constructions of childhood reflect an ambiguity regarding the social positioning of children in late modernity. Wyness (2005) describes children's status as dependent and subservient as a nostalgic attempt by adults to "recapture a sense of purpose and belonging" (pp 8) in the face of moral and social flux. Prout (2003) observed a "puzzled and anxious" mood towards children in contemporary Western societies and pointed to an ambiguity at the heart of the contemporary meaning of childhood due to the presence of two conflicting views. The first is an idealised view of childhood as a time of innocence. This is reinforced by sentimental images that circulate in public discourse of a fictional past where children were safe from harm. According to Prout (2003), media exaggeration of the risks that children face has prompted a spike in concern for protecting them from harm. This results in children's activities increasingly coming under adult surveillance and in children being quarantined from the public sphere. Contrasting images represent children as a threat to themselves and others, fuelled by sensationalised media reports on youth violence and public nuisance, and growing concern about bullying and cyber-bullying. Corsaro (2011) argues that children's actions, such as those depicted in media images of uncontrollable youth that are

consistent with the representation outlined by Prout (2003), are seen as evidence of a broader moral decay in adult society. Thus, even when children are represented as a threat, it is within a broader image of them as passive recipients of culture, not as agents of cultural change.

Sociology of childhood theorists call for child-centred research to remain mindful of the ways in which individual children's lives are shaped by the meanings held about childhood within the particular historical and social context in which they live. As social actors, children themselves shape their own lives and the lives of those around them. Children have perspectives on their worlds that are necessarily different from those held by the adults in their lives. In fact, as many researchers influenced by this theory have pointed out, there are some things about which children have greater expertise than adults, and this includes the experience of childhood contemporaneously (Christensen & James, 2000; Mayall, 2000; Moran-Ellis & Sünker, 2013; Prout & Hallet, 2003). Sociology of childhood theorists reason that if children are experts about their own lives then they ought to be actively involved in research about them, not only because it is their right to do so, but because it will result in more robust research (Qvortrup, 2004). The implication of this theoretical approach to the study reported in this thesis is discussed below.

4.3.4.   *Challenges for "child-centred" research*

According to Qvortrup (2005), a prominent contributor to the field, the sociology of childhood confronts a challenge about its ongoing contribution to childhood studies. While the theory is no longer regarded as "new" and has lost that prefix, he argues, it still has to defend its relevance by distinguishing itself from other academic disciplines which also focus on research about children or childhood. A conundrum at

the heart of the sociology of childhood is that it relies on a conception of childhood as a category that can be distinguished from other generational categories and, at the same time, insists that childhood can only be understood in terms of the specific context in which it is lived. As Jenks (2000) put it, "the 'socially constructed' child is inevitably a local phenomenon and tends to be extremely particular" (p. 69). Qvortrup (2000) stated that the challenge for researchers working within the framework of the sociology of childhood is to articulate "many childhoods" while holding a spotlight to shared childhood experiences and to the meaning of childhood itself. James (2005) added that sociologists of childhood need to remain focused on the political dimension of their inquiry, which is "underscored by the diversity of childhoods fractured by the major fissures of class, gender and ethnicity and by the relentless march of poverty on a global scale" (p. 4).

By implication, in the quest to articulate the diversity of childhoods, it is possible that anything common between children becomes obscured and the term *childhood* risks losing any categorical meaning at all. The potential limitation this poses for the study reported in this thesis, which explores the perspectives of a group of children, each of whom lives in a specific family, community, country and historical period, is acknowledged. To address this, the thesis is underpinned by bioecological theory which posits interaction between children and their immediate and more distal environments that also positions them within a broader social, cultural and historical milieu. Like the sociology of childhood, bioecological theory views children as agents who shape their worlds by their interactions with objects, people and symbols within their worlds. The next section describes the contribution of bioecological theory to understanding how children's social worlds are shaped by their experiences in multiple intersecting social contexts.

4.4. **Bioecological theory**

Bioecological theory describes the web of intersecting and enduring activities and interactions that take place between individual children and the people, objects and symbols in their immediate environments. These are influenced by the historical, cultural and social milieu in which they take place (Bronfenbrenner & Morris, 1998). The theory explains that it is necessary to see children within the totality of their social contexts to understand the ways that various factors influence their development. In bioecological theory, Bronfenbrenner acknowledged the role of biological characteristics and individuals' genetically determined potential play in their development (Bronfenbrenner & Ceci, 1994). Bioecological theory influenced a generation of child researchers to develop methodologies compatible with the aim of explaining environmental factors and their influence on children. Bioecological theory has commonly been used in empirical research (for a literature review see Tudge, Mokrova, Hatfield & Karnik, 2009). It is argued in this thesis that the theory is appropriate as an interpretive framework in qualitative research to understand the environmental influences on children's lives which, together with the sociology of childhood, attributes agency to children. The following section demonstrates the utility of this theory for this purpose.

4.4.1. *Origins of bioecological theory*

The origins of bioecological theory lie in Bronfenbrenner's earlier work, culminating in the publication of *The Ecology of Human Development* (Bronfenbrenner, 1979). This early work was extremely influential in Bronfenbrenner's own field of developmental psychology and more broadly in policy and research concerned with the impact of disadvantaged environments on children's lives (Bronfenbrenner, 2005). By presenting evidence for the prominent role played by environmental factors,

80

ecological theory challenged the then widely held belief that children's developmental outcomes were largely the result of genetics (Bronfenbrenner & Ceci, 1994). Bronfenbrenner (1979) believed that studying children in everyday settings like homes and schools makes it possible to examine the processes which promote or discourage their development. He criticised some quarters of developmental psychology for giving scant attention to the role of environment and famously described traditional developmental research as "the science of the strange behaviour of children in strange situations with strange adults for the briefest possible periods of time" (p. 19).

Ecological theory (Bronfenbrenner, 1979), the earlier model upon which bioecological theory was based, presents a conceptual model to describe the interactions between children and their environment that take place over time. The model proposes a nested structure and uses the image of a set of Russian dolls to explain that a child is surrounded by multiple social contexts, as the smallest doll is nested inside progressively larger dolls. Bronfenbrenner (1979) proposed four distinct systems in which the interactions surrounding a developing child take place. In the innermost circle, the microsystem, are the everyday activities and interactions between children and their immediate contexts, such as home, childcare or school. These interactions involve at least one other person, with mother-child dyads being the primary example and for which, as Bronfenbrenner explained, a "mutual, irrational attachment" is a critical ingredient (Bronfenbrenner & Morris, 1998, p. 1015). Interactions that take place when children transit between different environments, such as between home and school or the home of a school friend or a social group, introduce children to a mesosystem, the next of the concentric, nested circles. It is the fit between different settings that can invite opportunities for new activities, observations and interactions.

Microsystems and mesosystems involve direct interactions between children and their environments. The exosystem describes events that impact on children, but in which the child plays no direct role. Bronfenbrenner (1979) offered the example of a parent's workplace which can impact on children's lives by creating the need for childcare and by producing financial and other stressors which affect parents' interactions with their children. The fourth setting, the macrosystem, is the most distal setting and refers to cultural norms and beliefs of the society, which may be expressed through policies and laws that can affect the individual's development. For example, contemporary attitudes towards equal employment opportunities for women are expressed not only in industrial legislation, but also in child care policies such as fee subsidies, industry incentives and increased availability and images that promote positive views of this type of care.

The dimension of time was given recognition in ecological theory through Bronfenbrenner's (1979) emphasis on change to children and their environments over time. Subsequently, bioecological theory represented time as the chronosystem, which operates across all social systems and refers to changes in children and their environment over time, and the historical period in which children live and the duration and longevity of the activities and interactions in which they engage (Bronfenbrenner & Morris, 1998).

Despite its significant influence on developmental research throughout the 1980s, Bronfenbrenner became concerned that his theory had contributed to a research preoccupation with examining the social contexts in which children lived at the expense of examining the characteristics of children, including their biological potential. As Bronfenbrenner and Morris (1998) pointed out, this missed the point

about the development being an interaction between children and their environment. Bronfenbrenner re-evaluated his original model over the following two decades and it became known as bioecological theory (Bronfenbrenner & Ceci, 1995).

4.4.2. *The key elements of bioecological theory*

With bioecological theory, Bronfenbrenner placed greater emphasis on the processes by which children influence their environments and on the role of biology and genetics in influencing the extent to which environmental variables impact on child development. Biological differences are not the only influence on developmental outcomes for an individual but they do set limitations or confer benefits and interact with other features of children's specific environments. Bronfenbrenner and Morris (1998) devised a formula known as Process-Person-Context-Time (PPCT) to explain the ongoing interactions between a developing person and other people: objects and symbols (Process) which are affected by individual characteristics (Person) in a specific environment (Context) at a particular time (Time). Each of these four elements is now explained.

The first of the components of the PPCT formula is process. Proximal processes are the systematic interactions between people and their environment. These occupy a primary position in the formula because Bronfenbrenner determined these processes as "the primary engines of effective development" (Bronfenbrenner & Ceci, 1994, p. 572). Bioecological theory underlines the importance of proximal processes because it is through these that children gain understanding about their world and their own place within it. Processes include group and solitary activities and the people with whom these activities and exchanges occur. These vary, depending on the characteristics of the person and the features of the immediate environment, as well as

the social and historical period in which the child lives (Bronfenbrenner & Morris, 1998). To influence development, proximal processes need to happen regularly over an extended period and to be slightly beyond the child's current capability level (Bronfenbrenner & Ceci, 1994).

In summary, Bronfenbrenner (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 1998) argued that pattern of activities or interactions shape the way children understand the world. The influence of the pattern of activities or interactions can be positive, by creating an environment in which there are opportunities for children to reach their potential, to gain a sense of mastery and to develop new skills or reinforce positive beliefs about themselves. Proximal processes within children's environment also have the potential to produce less desirable outcomes. This happens when they do not provide appropriate learning opportunities for individual children or take the form of adverse or abusive processes that teach children to view themselves and the world in a negative way.

Person, in the PPCT formula, refers to the individual characteristics of children and the significant people with whom they engage in ongoing activities. Bronfenbrenner (Bronfenbrenner & Ceci, 1994) stipulated that the innate characteristics of an individual can significantly affect proximal processes by inviting or discouraging reactions from the social environment. Demand characteristics are the primary stimulus for proximal processes because they influence initial interactions by setting immediate expectations. Demand characteristics include innate features such as age, gender and physical appearance (Bronfenbrenner & Morris, 1998). Resource characteristics are personal traits like intelligence, skills and personal experience, along with access to material resources such as caring parents, adequate housing and

educational opportunities. Force characteristics are differences attributable to temperament and motivation. Bronfenbrenner and Morris (1998) explained that individual characteristics can hamper or promote proximal processes. As Bronfenbrenner and Morris noted, two children with identical resource characteristics can have very different developmental trajectories based on temperamental differences such as their motivation to achieve a particular outcome or their persistence with a task.

Context, in the PPCT formula, refers to the four interconnected systems that were described in the original ecological model, with the addition of the chronosystem. These systems include the immediate environments in which children spend most of their time engaged in activities and interactions, such as home, school, neighbourhood and peer groups, together with distal environments and their interrelations. Cultural contexts exert indirect influences on children's development and influence children through the value systems that they experience within microsystems (Bronfenbrenner & Morris, 1998). Bronfenbrenner and Morris (1998) outlined the importance of time in the PPCT formula. Time operates across all the systems. Micro-time is what happens in a specific episode of an activity or interaction. Meso-time refers to the consistency, frequency and duration with which this occurs over time, and macro-time acknowledges that processes vary depending on the historical period in which they occur, due to shifting cultural expectations and historical events.

Even in his earliest formulation of the model, Bronfenbrenner (1979) stressed the dynamic and bidirectional nature of interaction between developing children and their social contexts. This bidirectional nature of interaction underpins the conceptual

85

foundation of the current study about the social worlds of children of mothers with intellectual disability.

4.4.3.   *Mothers in their children's social worlds*

Bioecological theory assigns a central role to parents. This central role includes their direct interactions with their children and the resources and opportunities they make available for their children, which may be influenced by distal factors such as socioeconomic status. Resources include access to people, objects and symbols in the external environment. Bronfenbrenner and Crouter (1983) explained that parents' social networks affect children by providing other sources of information, emotional support and the exchange of goods and services such as childcare and supervision.

Bronfenbrenner and Ceci (1994) argued that environmental contexts influence children through the availability of resources and knowledge and the degree of stability and consistency they offers for proximal processes to be effective. Importantly, Bronfenbrenner and Ceci pointed to environmental conditions beyond the family as likely to be the most powerful and pervasive disrupters of family interactions. These sources of family stress can originate at the level of the macrosystem, in the form of discrimination, or extend beyond resources in the home to the kinds of activities that are available in "good" neighbourhoods and, conversely, the "risks" a neighbourhood may pose to a child (Bronfenbrenner & Ceci, 1994).

Bronfenbrenner and Morris (1998) explained that significant adults are those whose long-term commitment to a child's wellbeing and development can motivate that child to engage in the kinds of activities in physical environments that ignite the imagination, manipulation and exploration. Although parents are the quintessential adults with whom children have this type of bond, Bronfenbrenner (2001) pointed out

that the parent-child dyad depends on a third party to be most effective or, as he put it "in the family dance, 'it takes three to tango'" (Bronfenbrenner, 2001, p. 11). The role of this person, who may or may not be another parent, is to express support, assistance and admiration for the person engaged in activities with the child. This proposition by Bronfenbrenner (2001) is based on findings from investigations into the developmental outcomes for children raised in single-parent families. According to Bronfenbrenner (2001), the evidence supports the proposition that a third party is an "immunising" factor for children from single-parent families. The presence of relatives, friends, neighbours, members of religious groups and staff from family support programs not only provides children with greater attention but supports their parent to care for them.

The proposition that having access to another parental figure can provide children and their single parent, typically a mother, with an important source of support may be pertinent for the study of children of mothers with intellectual disability. Research about their social networks suggests that some mothers with intellectual disability may not have access to support from another reliable adult. Support networks are more likely to be stable and enduring when mothers are supported by a partner or close family member, and single mothers without family support may depend on formal services which, if episodic, may increase their risk of social isolation (Llewellyn & McConnell, 2002, 2004). Yet family support can also be viewed by mothers as unreliable, inappropriate or competence-inhibiting (Ehlers-Flint, 2002; Llewellyn et al., 2002; Stenfert-Kroese et al, 2002; Tucker & Johnson, 1989). Social support that does not match their needs may increase the risk of parenting stress for mothers with intellectual disability (Feldman et al, 2002) and this can impact on parenting practices (Aunos *et al.,* 2008; Wade *et al.*, 2011). Bioecological theory (Bronfenbrenner, 2001;

Bronfenbrenner & Morris, 1998) proposes an approach to understanding the influence of mothers and the home environment on their children.

4.5. **Conclusion**

This chapter describes the two theoretical frameworks that underpin the current study. The sociology of childhood and bioecological theory encourage us to understand the lives of children as constituted by their particular social contexts. In bioecological theory, children's temperament, skills, personal history and social contexts shape their responses to activities and their interactions with others. The sociology of childhood exposes the political nature of historical and social representations of childhood which have functioned to present and protect an adult-centred view of the world. Both theories call attention to the diversity of children's lived experiences in which lie the complex patterns of their social worlds. The next two chapters review literature about the social worlds of children in middle childhood, from studies informed by developmental psychology and the sociology of childhood.

CHAPTER 5: A DEVELOPMENTAL PERSPECTIVE ON THE SOCIAL WORLDS OF CHILDREN IN MIDDLE CHILDHOOD

5.1.   **Introduction**

The next two chapters establish the strength and limitations of research about the social worlds of children in middle childhood from studies conducted within two important research paradigms. This chapter addresses studies conducted within the field of developmental psychology and Chapter 6 reports on research findings that are informed by the sociology of childhood. The aim is to understand how the social context for mothers with intellectual disability, which may be restricted, can influence the social worlds of their children in middle childhood. In the previous chapter, bioecological theory and the sociology of childhood were discussed as two theoretical perspectives that provide a useful guide to the study of the social worlds of children of mothers with intellectual disability. In this chapter, these theories frame an exploration of the research literature which informs the current study.

Psychology has been a dominant paradigm in constructing childhood by research about child development, stemming from early theories by Piaget, Erikson, Vygotsky and others (see Burman, 2008). Ecological (Bronfenbrenner, 1979) and bioecological theory (Bronfenbrenner & Ceci, 1995) transformed child development research by illuminating a new way to view interactions between children and their developmental contexts. The notion of middle childhood is a construct of developmental psychology, making the developmental psychology research literature an appropriate place to commence this discussion.

The scope of this review is limited to permit a focus on research about the social experiences of children. Studies were selected based on their contribution to

understanding the influences that shape the social worlds of children in middle childhood. Substantial literature deals with several social contexts examined in this chapter, such as peers. Studies were selected based on their relevance to the particular developmental stage of middle childhood. It was beyond the scope of this review to also stratify studies by characteristics such as gender and ethnicity.

### 5.2.	**Middle childhood as a developmental stage**

The term *middle childhood* refers to a stage of childhood that developmental psychologists associate with the period between approximately 6 and 12 years of age (Collins, 1984). For most Western developed nations, middle childhood corresponds with the age at which children start school and precedes the onset of adolescence (Huston & Ripke, 2006). This life-stage has particular importance in the social development of children as it is the time in which their social worlds generally expand to include many more influences beyond the home.

In the first national investigation dedicated to middle childhood development in the USA, Collins (1984) claimed that "the implicit grouping of ages 6-12 appears to be neither an idiosyncratic invention of Western cultures nor merely a category by default among arbitrarily defined periods of human development. Rather, these years universally mark a distinctive period between major developmental transition points" (p. 1). A focus for those within the developmental psychology tradition is to understand the ways in which this life-stage contributes to the skills that children will need to establish positive developmental pathways as they move into adolescence and beyond (Huston & Ripke, 2006). The work of Bronfenbrenner sits within this developmental psychology framework.

90

5.2.1. *Bioecological theory and middle childhood*

Bronfenbrenner (1979) issued a challenge to developmental researchers to view children as inseparable from their developmental contexts. Bronfenbrenner criticised traditional, lab-based developmental psychology research as uni-dimensional and often unable to explain the multiple and overlapping developmental influences in the lives of children. From his perspective, child development should be viewed not only in terms of the normative skills children gain at particular stages, but in terms of the processes that promote, enhance or constrain developmental opportunities. Bronfenbrenner (1979) argued that children were influenced not only by the proximal environments but also by more distal cultural, historical and social forces. These factors shape the cultural and social contexts in which children live and include values, norms and beliefs that are embedded in social structures, such as mass media, legal institutions and government policies. Macro and exosystem factors (as described in Chapter 4, p 113) impact on everyday settings for children in ways that can promote or inhibit their capacity for positive learning experiences.

Later, with bioecological theory (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 1998), Bronfenbrenner stressed the importance of seeing children as actors in the reciprocal, person-environment dynamic that shapes their social worlds, not as passively acted upon by external forces. Physical and temperamental characteristics of children interact with features of their environment to influence their social interactions (Bronfenbrenner & Morris, 1998). From this perspective, research that singles out any one social context for investigation inevitably risks distorting or ignoring the role of other environmental influences. The expansion of social contexts for children in middle childhood increases the diversity of potential environmental influences beyond the home. From this perspective, seeing children only in terms of

the social context of their mothers, including those with intellectual disability, presents a partial, potentially misleading picture of their social worlds.

From a bioecological perspective (Bronfenbrenner & Ceci, 1994), children gain competence when their particular needs and the demands of the environment are congruent. This principle is illustrated in a study by Tietjen (1989) that provides an example of the importance of examining child development with an understanding of the contexts in which it takes place. Tietjen compared the support networks of 73 urban Swedish children and 25 children from the Maisin, a traditional Papua New Guinean tribe. According to Tietjen (1989), Swedish children tended to have few close social ties, which were centred on immediate family. Immediate settings, such as child care and school, supported children to develop individuality and form social connections with a large number of relatively weak ties. Support that was most adaptive to children in this environment was that which enabled them to develop self-esteem and problem solving ability. In contrast, the social network of a Maisin child was likely to include a large number of close kinship ties, based on a typically large family size and a collectivist social organisation. Instrumental support, in response to an ecological context in which physical survival needs dominated, was a priority. Children in both environments developed competence that was appropriate to their particular circumstances when environmental demands and social support aligned.

5.3.   Important social contexts in middle childhood

Research investigating contextual influences in middle childhood most often focuses on the immediate everyday settings of home, school and neighbourhood (e.g., see Cooper, Coll, Bartko, Davis, & Chatman, 2005). Although the children of mothers with intellectual disability have not been a specific focus in this body of research, it

informs an understanding of the influence of important people and contexts in children's lives. Reviews of research about home, school and neighbourhood environments in middle childhood are presented in turn. Given their significance in middle childhood, a section is also devoted to the influence of peers.

5.3.1.   *The influence of the home in middle childhood*

Home is argued to be the key learning environment in early childhood, as attested by systematic reviews concerning the importance of early mother-child interactions (Kendrick, Elkan, Hewitt, Dewey, Blair *et al*., 2000: Maas, Vreeswijk, & van Bakel, 2013; Poobalan, Aucott, Ross, Cairns & Smith, 2007). There are undoubtedly other important learning environments for young children, such as early childhood education and care settings. However, the home environment has been seen by researchers informed by attachment (Bowlby, 1969) and social learning (Bandura, 1971) theories as having the primary influence on children's social worlds in these early years (Harden & Whittaker, 2011; Hindman & Morrison, 2012; Morrison, Rimm-Kaufman & Pianta, 2003). Middle childhood is a time of transition in many ways, and it includes expansion of the environments that exert an influence on the social worlds of children. The quality of the home environment remains crucial, but other environments now compete for influence.

Literature that highlights the influential role of social environments for children could indicate that restrictions on mothers' social contexts may impact on the social worlds of their children. But, as limited research directly addresses this question, more general research about the influence of mothers on the social worlds of their children in middle childhood may prove instructive. From a bioecological perspective (Bronfenbrenner & Morris, 1998), parenting is a bidirectional process in the sense that

it is dynamic between a particular child and their parent/s. As Gallagher (2002) put it, "the child is an active participant in the parenting process" (p. 627). For example, a child who is having problems with friends or peers at school may manifest unhappiness in difficult behaviour at home. In this case, through interactions that take place elsewhere, a child can influence parenting practices at home (Dunn, 2004).

Researchers have examined the association between maternal characteristics, a mother's social environment, and developmental outcomes for her child. The focus of research about the influence of mother-child interactions on peer interactions in middle childhood has been on maternal social support, peer relationships, and management of their children's peer relationships. A meta-analysis by Schneider, Atkinson and Tardiff (2001) reported a correlation between parent-child attachment and children's peer relationships in 63 studies that addressed this issue. The association between early attachment and friendships was strong, especially for close friendships in middle childhood and adolescence. The influence of mother-child attachment on friendship quality in middle childhood was recently examined using longitudinal data collected about 336 children and their mothers (Blair, Perry, O'Brien, Calkins, Keane et al., 2013). The authors examined whether changes in children's ability to regulate their emotions early in middle childhood were associated with changes in friendship quality by late middle childhood. The study focused on mothers as the primary agents of emotion socialisation, as they modelled interactional responses. Mothers' emotion socialisation practices were found to play a role in their child's emotional regulation in middle childhood. Children whose mothers provided supportive emotion socialisation in early middle childhood demonstrated higher emotion regulation 2 years later. Supportive maternal emotion socialisation, such as accepting children's negative emotional displays and helping children cope with

negative emotions, enabled children to practise regulation prior to encountering emotionally charged situations with peers. Greater emotional regulation skills increased the likelihood of high-quality friendships for children. Findings from this study indicate that the quality of mother-child interactions may be an important influence on children's social skills.

Social support has been found to influence the quality of mother-child interactions. Social support mediates parenting stress for disadvantaged parents (Attree, 2005) and has an indirect influence on children through increased positive parenting practices (Andresen & Telleen, 1992; Grimes, Klein & Putallaz, 2004). Parents' social relationships exert an influence on children through an effect on parenting practices and shape the lessons parents impart to their children about social interactions. In support of this proposition, some studies have found a positive relationship between the size and quality of the friendship networks of parents and their children. Uhlendorff (2000) reported a positive relationship between the friendship network size of 7–12 year olds and their parents. The number of friends with whom parents said they spent leisure time was associated with the number of their child's non-school friends. Simpkin and Parke (2001) reported a positive association between the quality of friendships for parents and quality of friendships of their 9-year-old children.

Research suggests that mothers exert greatest control over the social networks of their children in early childhood (Grimes, Klein & Putallaz, 2004), and their knowledge about their children's peer networks diminishes during middle childhood. Feiring and Lewis (1989) found that mothers were less familiar with their children's friendship networks at the end of middle childhood than they were at the beginning. However, other research suggests that in unsafe neighbourhoods mothers may extend their

control over the social networks of their children into adolescence (Ingoldsby & Shaw, 2002). It has been established that mothers continue to be a primary attachment figure for their children in middle childhood (Seibert & Kerns, 2009), and the security of attachment to parents predicts children's self-esteem and life satisfaction in middle childhood (Nickerson & Nagle, 2004). Seibert and Kerns (2009) reported on changes to children's attachment behaviour toward their mothers in middle childhood. They sought nominations from 114 seven- to twelve-year-olds about important people in their lives and who they would seek out in attachment or companionship situations. A shift away from the primacy of mothers as attachment figure and a greater companionship role for peers in middle childhood was reported. Children's decisions about who could fulfil their attachment needs became more context-dependent as the importance of peer companionship emerged.

In summary, this literature is useful for the current study by its explanation of the influence of maternal social support and the quality of the home environment on children. That social support and social network size for mothers influence their children (Simpkin & Parke, 2001; Uhlendorff, 2000) is important in the context of other research indicating that some mothers with intellectual disability may have small social networks, few friends, and be at risk of social isolation (Llewellyn, 1995; Llewellyn & McConnell, 2002; Llewellyn et al., 1998; Stenfert-Kroese et al., 2002). Research indicating that the quality of the home environment can mediate the negative effects of low socioeconomic status on children's learning (Huesmann et al., 2006; Vortruba-Drzal, 2006) is relevant in the context of research about the home environment of children of mothers with intellectual disability (Feldman & Walton Allen, 1997; Wade et al., 2011; Wise, 1997). Given some evidence that children benefit from the social opportunities derived from their parents' social networks

(Grimes et al., 2004), the social worlds of children whose mother with intellectual disability is friendless may be potentially restricted.

5.3.2. *The influence of school in middle childhood*

Starting school is a major life transition for all children, including those who have attended child care or pre-school (Dockett & Perry, 2001). School is an environment in which children spend a substantial amount of their time in the company of non-related adults and peers (Chipuer, 2001). One key difference between school and home is the disproportionately higher ratio of children to adults at school (Stipek, 2005). Going to school introduces new transitions between the home, school and neighbourhood. This may include visits to the home of a school friend, encountering peers on school buses, making friends in the neighbourhood, and mothers interacting with teachers and other parents at school. Arguably the most significant influence exerted by school on the social worlds of children is through the time that school children spend in the company of peers. This section discusses the influence of teacher-child relationships and the school setting on the social experiences of children.

School experiences in middle childhood can influence children's future attitudes toward learning, and their typically positive feelings about school in middle childhood appear to diminish during adolescence (Nickerson & Nagle, 2004). In a study about sense of belonging in middle childhood, Chipuer (2001) examined parental attachment and connection to neighbourhood and school and found that school belonging was the only significant predictor of children's loneliness. Feelings of alienation at school can have a great impact on children's psychological wellbeing because most of their waking time during the week is spent in this environment. The classroom is an important setting, at least in part because children who are socially rejected in this

97

context cannot escape negative peer sentiments and behaviour (Ladd & Troop-Gordon, 2003).

The availability of material resources and teacher quality varies across individual classrooms and different schools (Garcia Coll & Szlacha, 2004). In this way, the same school can present a child with differential learning opportunities, and different school environments can promote or inhibit learning. The quality of teacher support is a potentially influential aspect of the school setting in relation to children's peer interactions, and one which has received relatively little attention. Demaray, Malecki, Rueger, Brown and Summers (2009) found a significant relationship between children's self-concept and the frequency of support from parents, teachers, classmates and friends among a large representative sample of school-aged children and adolescents. The importance that children placed on socially supportive behaviours from teachers, but not parents, predicted positive self-concept. In contrast, the influence of support from classmates on self-concept depended on the value that a child placed on it. This may represent a potentially protective function in which the value of peer support is diminished in its absence.

The relationship between children and teachers influences not only children's academic achievement but also their social experiences at school. Stoekli (2010) found that classroom participation predicted self-esteem for children experiencing classroom loneliness. Classroom loneliness for socially withdrawn or anxious children can be more effectively reduced if teachers promote their classroom participation rather than focusing on their withdrawn or anxious behaviour. Berry and O'Connor (2010) added to an understanding of the influence of teacher-child relationships on the development of children's social skills. In their study, children with higher-quality

teacher-child relationships demonstrated better social skills throughout middle childhood than their peers with lower-quality relationships with teachers. However, other research suggests that a positive relationship with teachers might not improve the status of victimised children with peers. Troop-Gordon and Kopp (2011) examined the extent to which characteristics of the teacher-child relationship, namely closeness, dependency and conflict, predicted changes in children's peer victimisation and aggressive behaviour over a school year. The findings indicated that a poor-quality teacher-child relationship in late childhood was predictive of physical but not relational aggression. Dependency on the teacher predicted more peer victimisation but a close relationship with the teacher forecast less physical aggression toward peers. A close teacher-child relationship was not found to protect against subsequent peer victimisation; the authors postulated that the skills fostered within teacher-child relationships might not be conducive to preventing peer hostility.

To summarise the implications of these findings for the current study, the literature reviewed indicates that children spend much of their time at school in middle childhood and this social world becomes highly influential for them. Schools impact on children through the quality of the learning environment (Garcia Coll & Szlacha, 2004), and teachers can become an important source of support and emotional security (Troop-Gordon & Kopp, 2011). High-quality teacher-child relationships may improve the social skills of some children (Berry & O'Connor, 2010) and increase classroom participation for socially withdrawn children (Stoekli, 2010). However, a good relationship with teachers might not improve the peer status of socially rejected children (Troop-Gordon & Kopp, 2011). Overall, the research reviewed makes clear that schools have a potentially protective role for children experiencing difficulties with peers. The school environment can substitute for inadequacies in the support

available in the home. This may be relevant in the context of children of mothers with intellectual disability. Currently, findings about the school experiences of these children are limited. In two retrospective accounts from adults, first Booth and Booth (1998) reported that children's negative experiences at school could lead to early school leaving and second Ronai (1997) talked of her strategies to disguise her mother's intellectual disability from her school friends and their parents. In the only study conducted with children of parents with intellectual disability, Faureholm (2010) reported experiences of ostracism and noted that access to a structured, community-based educational program after formal schooling ended, could improve adolescent self-esteem.

5.3.3.   *The influence of peers in middle childhood*

The significance of friendship has been well established in the peer relationship literature (for reviews see Berndt, 2004; Rubin, Bukowski, & Parker, 2006a). Middle childhood is regarded as a formative period for the emergence of friendship. By the end of this period, children's friendships have taken on the qualities of intimacy that characterise adolescent and adult relationships, such as reciprocity, mutual influence and shared history (Rubin et al., 2006a). Making friends is seen as a child's first experience with meaningful relationships that are truly voluntary (Kupersmidt & Dodge, 2004). The early school years are a formative period for the development of self-belief about peer acceptance. Ladd and Troop-Gordon (2003) examined associations between children's disposition, self-image and internalising or externalising problems across middle childhood. Significant associations emerged between chronic friendlessness and peer rejection and children's later adaptation. Positive self-beliefs partially mediated the relationship between peer difficulties and internalising problems and loneliness.

Peer relationships include group dynamics and dyadic friendships. Peer group acceptance is generally based on the majority opinion of a group about a child; friendship is based on the positive sentiment two children share which indicates that reciprocated, positive feelings exist between themselves and at least one peer (Bukowski & Hoza, 1989). Peer rejection, or being disliked by the group, is different from being friendless or having problems in a close friendship (Rubin et al., 2006a). Dunn (2004) makes the point that children who are not particularly popular often enjoy satisfying friendships while not all popular children have a close friend. In a seminal study about friendship, Parker and Asher (1993) evaluated the influences of dyadic friendship and peer acceptance on friendship quality. They examined the peer acceptance of 800 school children who were ranked as low, average and highly accepted. The study found that most children had at least one friend but low accepted children were significantly less likely to have a friend or best friend. Children without best friends were found to be lonelier than those with best friends, regardless of how well accepted they were by the peer group. The friendships of rejected children were likely to be less stable, supportive and intimate than those of popular children.

Peer relations research has examined the influence of different types of friendship quality on children. Berndt (2004) explains that friendship quality consists of positive dimensions, such as intimacy and validation, as well as negative dimensions, such as conflict and betrayal. High-quality friendships have been found to increase children's life satisfaction and subjective wellbeing (Nickerson & Nagle, 2004). Recent research has examined the impact of differences in the quality, stability and size of children's friendships and the influence of child characteristics on peer acceptance and friendship. For example, Wojslawowicz-Bowker Rubin, Burgess Booth-LaForce and Rose-Krasnor (2006) examined the association between best friendship patterns in

relation to friendship loss and replacement, and children's social and emotional adaptation. Findings suggested that having any best friend over time may be as important to children's adjustment as same-friendship stability. Best friendship loss, when not followed by best friendship replacement, may lead to increased adjustment difficulties. In research about the association between peer acceptance or rejection and friendship, Malcolm, Jensen-Campbell, Rex-Lear and Waldrip (2006) examined the contributions of peer acceptance and friendship network size and quality to peer victimisation. They found that peer acceptance and high-quality friendships negatively predicted both overt and relational victimisation.

Peer rejection and victimisation, or bullying, present significant risks to children's wellbeing (Dunn, 2004). Being rejected by peers has been found to predict greater psychological maladjustment than friendlessness (Klima & Repetti, 2006). Dunn (2004) explained that the often surreptitious nature of peer victimisation makes its prevalence difficult to determine. However, some evidence suggests it is relatively stable over time. Children who are actively disliked by peers face greater risks to their wellbeing than those who are neglected, since the peer status of this latter group is more mutable (Dunn, 2004). Children who are actively disliked include those who are aggressive and controlling or awkward and socially withdrawn (Sandstrom & Zakriski, 2004). The impact of peer rejection on children's social worlds depends on the children themselves and their environment.

Researchers have examined the antisocial traits of aggressive-rejected boys' friendships (Bagwell & Coie, 2004) and the influence of peer rejection on aggressive behaviour over time (Cowan & Cowan, 2004). Erath, Pettit, Dodge and Bates (2008) found that involvement in a "mutual dislike dyad" in second and third grade was

associated with higher levels of aggression for boys in late middle childhood. Cowan and Cowan (2004) found concurrent and lasting links among aggression, peer rejection, social skills and antisocial behaviour over the first 4 years of school. Bagwell and Coie (2004) compared aggressive and non-aggressive boys' friendships and observed that non-aggressive boys and their friends had more positive engagement, task-focus and reciprocal interactions than aggressive boys and their friends. Aggressive boys and their friends provided more enticement for rule violations and engaged in more rule-breaking behaviour than did non-aggressive boys and their friends.

Children who are withdrawn are also at risk of peer rejection. Social withdrawal has been found to be a stable phenomenon throughout middle childhood, and socially withdrawn children appear to be at increased risk of internalising behaviour and lower self-esteem (Rubin & Coplan, 2004). Rubin, Wojslawowicz, Rose-Krasnor Booth-LaForce and Burgess (2006b) explained that the behaviour of shy and wary children contributes to their rejection by peers, which leads to lower self-esteem and creates greater anxiety and increased social withdrawal. However, support from a best friend has been found to predict a decline in social withdrawal over time (Oh, Rubin, Burgess, Booth-LaForce & Rose-Krasnor, 2004), and withdrawn children have been found to be as likely as their peers to have mutual stable best friendships (Rubin, Wojslawowicz, Rose-Krasnor Booth-LaForce & Burgess, 2006b).

High-quality friendships can mediate the impact of some contextual difficulties, such as peer victimisation and family adversity. Schmidt and Bagwell (2007) examined friendship quality as a mediator in the association between peer victimisation and internalising distress. Both overt and relational victimisation were associated with

anxiety and depression. Supportive friendships moderated the association between victimisation and psychological adjustment. The extent to which friendship provides a buffer against the negative effects of family adversity remains unclear. One study found that boys from divorced families had fewer friends and lower quality friendships than boys from non-divorced families (Lindsay, Colwell, Frabutt & MacKinnon-Lewis, 2006). It may be the case, however, that children who cope better with their parents' troubled relationships are also better at making and keeping friends (Dunn, 2004). Criss, Pettit, Bates, Dodge and Lapp (2002) reported more positive findings about the influence of friends on children facing family adversity, such as low socioeconomic status, harsh parenting discipline and marital conflict. Peer acceptance moderated all three indexes of family adversity and externalising behaviour. Peer relationship was a stronger predictor of social skills than family factors.

To summarise, these findings indicate that friendship and peer acceptance appear to independently predict child wellbeing. Being friendless and rejected by peers predicts the greatest current and future risks for children (Dunn, 2004). High-quality friendships may buffer children against some forms of family adversity (Criss et al., 2002) and peer difficulties (Rubin et al., 2006a; Schmidt & Bagwell, 2007). Aggressive friendships can reinforce the anti-social behaviour of boys in middle childhood (Bagwell & Coie, 2004) and early peer rejection can entrench peer difficulties for aggressive (Cowan & Cowan, 2004) and withdrawn children (Rubin et al., 2006b).

The findings about peer acceptance and friendship in middle childhood and over time are important for this study of children of mothers with intellectual disability because

little is currently known about their experiences with peers. Although peer rejection

has been noted by adult participants (parents with intellectual disability) in a few

retrospective studies (Booth & Booth, 1998; Faureholm, 2010; Ronai, 1997), there is

little research to guide understanding about the social experiences or peer

relationships of children of parents with intellectual disability in middle childhood.

The relationship between stigma and self-esteem has been investigated by Perkins et

al., (2002) and between maternal stress and behaviour problems by Aunos et al.,

(2008) and Feldman and Walton Allen (1997). With only three studies, with different

research designs and limited samples, research about children of mothers with

intellectual disability in middle childhood is in its infancy. It is not yet clear whether

the findings from the research reviewed above and conducted with other children

apply to children growing up with mothers with intellectual disability.

5.3.4.   *The influence of neighbourhoods in middle childhood*

Early research has established that children's use of and connection to the

neighbourhood expands in middle childhood (Chawla, 1992; Shaivo, 1988). More

recently, it has been shown that neighbourhoods become a significant part of a child's

sense of place and belonging in middle childhood (Scourfield, Dicks, Holland,

Drakeford & Davies, 2006). Neighbourhood quality has been shown to influence

children directly through exposure to the attitudes and behaviour of peers and adults in

the local area and to influence them indirectly by its impact on their parents

(Ingoldsby & Shaw, 2002). Ingoldsby and Shaw (2002) reviewed empirical studies

that measured neighbourhood factors and assessed a developmentally appropriate

dimension of antisocial behaviour with a large proportion of participants in middle to

late childhood. The purpose was to examine findings about the influence of

neighbourhood economic disadvantage, exposure to violence and antisocial peers on

antisocial behaviour in middle childhood. Neighbourhoods characterised by economic decline, population turnover and decreased family resources had lower levels of both formal and informal control and poorer collective efficacy. These conditions were thought to facilitate greater access for children and adolescents to an antisocial subculture, which was associated with the early-onset of antisocial behaviour in middle childhood and subsequent increases in serious delinquency (Ingoldsby & Shaw, 2002).

Maternal perceptions of neighbourhood risks can affect not only their child's peer relationships in the neighbourhood but their social skills. O'Neil, Parke and McDowell (2001) examined the role of maternal perceptions of neighbourhood characteristics in parental regulation of children's activities and children's social competence. Their study involved interviews with 63 mothers about supervisory strategies and rules about neighbourhood access for their child. Children's social adjustment was assessed using standard sociometric protocols, teacher ratings, and a self-report loneliness questionnaire. Mothers' perceptions of poorer neighbourhood quality were found to be related to children's social skills and perceived loneliness. Children also reported greater supervision of their activities in neighbourhoods that mothers perceived in a more negative light. Although neighbourhoods with fewer resources and more social problems appear to restrict opportunities for children, the presence of structured programs can enhance these environments for children. Morris and Kalil (2006) reported that participation in structured after-school activities such as sports, lessons and clubs, was associated with more prosocial behaviour among children in socioeconomically disadvantaged neighbourhoods.

In summary, the findings show that children's use of neighbourhoods expands in middle childhood but their opportunities for access to the neighbourhood may be restricted by their mother's perception of the neighbourhood as unsafe or unsuitable. Mothers appear to regulate their children's access to the neighbourhood as a function of perceived neighbourhood quality (O'Neil et al.*,* 2001). In neighbourhoods which they perceive to present safety risks and antisocial elements, mothers may restrict their children's contact with peers and activities (Ingoldsby & Shaw, 2002). Children of mothers with intellectual disability are likely to be living in relatively disadvantaged neighbourhoods. Most studies investigating the social context of mothers with intellectual disability were conducted with mothers from relatively or severely disadvantaged backgrounds (see Chapter 2, p. 41-45). Therefore, a finding that neighbourhood disadvantage potentially exposes children to antisocial peers may be pertinent.

5.4.   Conclusion

This chapter has discussed research from the field of developmental psychology in relation to the important roles of home, school and neighbourhood in the development of children's social worlds in middle childhood. Findings have been examined to understand the ways in which these social contexts exert an influence on the learning and social opportunities available to children, depending on characteristics of the children and their environment. In the interest of establishing empirically reliable findings, developmental psychology research primarily employs quantitative methods. This approach does not permit an appreciation of the subjective experience of individual children and their perceptions and experiences of social worlds. Children are agents in their social worlds and their position as children represents a unique perspective on childhood which warrants research attention. In the next chapter I turn

to research informed by the sociology of childhood. This perspective illustrates the active role children play in their world as individuals in their own right, not as incomplete adults. This theoretical approach will be employed in this thesis to understand how children view particular influences in their lives.

CHAPTER 6: A SOCIOLOGY OF CHILDHOOD PERSPECTIVE ON THE SOCIAL WORLDS OF CHILDREN

6.1.   **Introduction**

This chapter outlines research conducted from the sociology of childhood perspective about the social worlds of children. This complements the developmental literature presented in the previous chapter about the social contexts of home, school and neighbourhood in middle childhood. Taken together, literature from both perspectives enhances understanding of how children navigate their everyday lives, including the people in their everyday lives. No claim is made to represent a definitive children's viewpoint. From the sociology of childhood perspective, such an endeavour would deny the multiplicity of childhoods. Rather, this chapter extends the preceding examination of middle childhood by presenting research that contributes to an understanding of childhood as seen from a child's perspective. The purpose of reviewing these studies informed by the sociology of childhood is to demonstrate that different understanding can be gained by using methods that enable children to express their perspective. The focus is limited to studies about the everyday life for children in high income countries because this is where research of this type has taken place.

6.2.   **Critique of the developmental approach to childhood**

As Chapter 5 demonstrated, substantial knowledge has been gained from developmental research about environmental influences that shape the social worlds of children. Nevertheless, prominent sociologists of childhood have long criticised the developmental approach. For example, James, Jenks and Prout (1998; Prout & James, 1997) claimed that it is limited by a positivist belief that childhood is a natural and

universal state (Prout, 2005). Mayall (1996) argued that psychology attempts to definitively explain the motivation for all children's actions, and Woodhead (1996) claimed that proponents of "development" use the word to imply that change occurs according to a designated pathway. Developmental psychology positions childhood in opposition to adulthood. In this dichotomy, children appear to be "human becomings" (Qvortrup, 2005) or incomplete adults, rather than people in their own right (Prout & James, 1997).

One key feature of this critique is the rejection of a view of childhood seen through the lens of developmental periods. As a result, the notion that childhood can be segmented into a life stage called middle childhood does not align with the sociology of childhood perspective. James (2005) argued that applying a standard developmental and chronological pathway for all children leads to labels such as "delayed" being applied to children who do not conform to the rigid timeline. The "mythology of the developmental model" that James (2005) referred to is reflected in Collins' (1984) assertion, quoted in Chapter 5, that "these years *universally* mark a distinctive period" (p. 1, my italics). Throughout this thesis, the term middle childhood has been used in recognition that it is familiar to many readers. It does not imply acceptance of assumptions about normative developmental stages associated with a developmental perspective on childhood. Rather, use of the term permits a dialogue between two theoretical fields that share an interest in understanding the experiences that shape children's lives. In this chapter, the research that is considered includes children around the ages of 6–12 years and explores children's perspectives of their social worlds, including studies with a focus on social experiences or children's views of wellbeing and life satisfaction.

6.3. **The contribution of children's perspectives in research**

The sociology of childhood has also directed criticism toward its own discipline for the relative absence of children's voices from sociological research (Holloway & Valentine, 2000; Prout, 2005). Over recent decades, and partly in response to recognition of this absence, a growing body of sociology-informed research has accumulated that demonstrates the substantial gains that follow from hearing children's perspectives on issues that concern them. Chapter 7 outlines research methods that facilitate the meaningful and active participation of children in research. It is now well understood that research that presents findings about what children view as influences on their health, wellbeing and everyday life can be used to shape policies and program interventions. For example, research that seeks children's views about their diet and activity levels can add to existing knowledge that aims to improve their physical activity and healthy eating (Husby, Heitmann & O'Doherty-Jensen, 2008; Mier, Lee, Smith, Wang, Irizarry et al*.,* 2013; Pearce, Kirk, Cummins, Collins, Elliman et al., 2009).

Willenberg, Ashbolt, Holland, Gibbs, MacDougall and colleagues (2010) explored the environmental characteristics that influenced children's lunch-time activity levels at school by observing children at play as well as seeking their views in focus groups. These methods enabled them to identify relatively simple changes that would provide opportunities for increased physical activity, such as the availability of loose rather than fixed equipment, which had not been identified when other research methods were used. Elliot (2011) conducted focus groups to obtain children's views about food to examine the influence of child-oriented food marketing strategies on children's perspectives on food. She found that children viewed unprocessed fruits, vegetables and meats as "adult foods"; the "fun" foods that they saw as being for children were

processed, sugary and low in nutrients. Husby and colleagues (2008) explored children's views about eating habits by getting them to photograph their meals and snacks and then conducting semi-structured interviews. They found that the meals of children with healthy eating habits were shared social events and their intake of nutritionally poor foods was quarantined for special social occasions. Gaining children's perspectives made clear that interventions to promote children's healthy eating should focus more on the different social contexts of food consumption and the role of parents in fostering healthy eating habits.

Children's perspectives can also be used to tailor more child-responsive programs and policies. Fattore, Mason and Watson (2009) conducted participatory action research with children using a multi-stage approach in which data from initial interviews with children was used to inform subsequent interviews that explored themes using creative methods. The study was designed to guide the development of a child wellbeing monitoring framework. Significant relationships were central to the way children viewed emotional wellbeing. Children recognised that their desire to be involved in decisions about what affected them had to be balanced against their security and safety needs. The importance that children attributed to being socially responsible citizens was an aspect of wellbeing that had not previously been reported in research conducted using other methods. According to Fattore et al. (2009), this demonstrates that child-centred research methods can yield different findings or findings that contradict those from an adult perspective. Similarly, when Rose (2006) asked children about their views of interventions designed to help them, she found that children wanted more control over situations and greater involvement in decisions affecting them. By hearing from children it emerged that they wanted professionals to take a holistic view of their life, not just focus on their problems (Rose, 2006).

Seeking the views of children about issues that are important to them and that they are uniquely positioned to understand contributes to research that can guide policy agendas (Fattore et al., 2009). This is salient in the context of research about a group of children whose views have rarely been sought and who, according to international research are at heightened risk of being removed from their mothers with intellectual disability (Booth et al., 2005; Llewellyn et al., 2003; Taylor et al., 1991). Seeking their perspectives adds another perspective on the multiple influences that promote, constrain or discourage learning opportunities to enhance their lives. Hearing about social worlds from these children means that information about their mothers is not filtered through an adult-centred lens which, as the literature review in Chapter 2 noted, may be skewed by the attention paid to the mother's intellectual disability. Hearing the children's views about their social worlds creates an opportunity to learn about significant and possibly unexpected interactions between individual children and their particular environments that may illuminate influences at play for this group of children.

6.3.1.   *Children's perspectives of home, school and neighbourhood*
According to Holloway and Valentine (2000), time and place are central categories in conceptualising everyday life for children. Corsaro (2005) observed that there has been a reduction in free time and increased participation in organised activities for children in high-income countries over recent years. This represents a change to the ways that children organise their time and daily lives and this change has been a focus of attention in research to understand their views of social worlds (see e.g., Karsten, 2003; Rasmussen, 2004; Zeiher, 2003). The intersecting settings of home, school and neighbourhood form what Rasmussen (2004) referred to as the "institutionalized triangle" of children's everyday lives in Western nations. Literature from the

113

sociology of childhood suggests that children perceive school as imposing greater restrictions on their freedom of movement and autonomy than home (Mayall, 1996; Rasmussen, 2004).

6.3.2. *Intersecting social worlds of home and school*

Mayall (1996), a pioneering contributor to research focused on the everyday lives of children from their own perspectives, explored children's views about the social worlds of home and school. Mayall used interviews, drawings and writing by children 5 and 9 years old, as well as interviews with their mothers, to explore children's perceptions of the differences between home and school. School-based learning was seen as abstracted from everyday life whereas home-based learning took place in the context of family routines and needs. Children perceived themselves to have greater autonomy and ability to negotiate rules at home than school. The children viewed their mothers as the person with whom they negotiated rules; their mothers saw their self-care instruction for children, which was aimed at increasing their child's autonomy, as mutually beneficial. Teachers, in contrast, were see by children as enforcing control over daily school routines. They demanded conformity to rules that restricted children's movements in regard to such matters as the timing of toilet, meal and physical activity breaks.

Children may view the social world of school in terms of social interactions with peers and teachers, but their experiences are also shaped by the physical space of the playground (Rasmussen, 2004). Rasmussen (2004) used child-centred research methods, including Photovoice, to investigate Danish children's experiences of everyday life at school, home in formal recreational settings. Rasmussen explained that Danish school playgrounds are typically cemented areas surrounded by high

fences, containing few playthings. This environment is more strikingly uniform than the places children establish for themselves at home. Although adult rules about where children could go in the school playground restricted their movements, children actively navigated this to designate spaces as their own. As these spaces were frequently not those which adults saw as "places for children", recognition of their significance for a child could only be learned directly from talking to the children using them.

Structured after-school activities, such as team sports and music classes, recreation centres or clubs are a common part of many children's everyday life (Rasmussen, 2004). Corsaro (2005) noted a growing trend for children to spend a substantial part of their leisure time in structured recreation settings. One child in the study by Rasmussen (2004) reflected that they sometimes "take the day off and stay at home" rather than go to the recreation centre, demonstrating that it was perceived as a structured environment similar to school rather than as free time. In a study that explored children's use of free time, Zeiher (2003) reported that children made decisions about how to spend their time in concert with their parents whom they saw as "negotiation partners". Children perceived themselves as having autonomy despite the restrictions that parents placed on their time use and on the distance they were allowed to travel from home.

The so-called "information revolution" that has occurred over recent decades has seen children's use of computers in classrooms and at home grow exponentially as computers become a part of everyday life for many children (Holloway & Valentine, 2000). The push to provide children with access to computers and the internet at school is based on a belief that their future employment and economic prosperity rely

on computer literacy (Cassell, 2004). Cassell (2004) argued that research has demonstrated both benefits and harmful effects of computer use in children, leading to contested perspectives on the positive or negative outcomes of computer use. A recent example of its negative influence was reported in a study by Mier and colleagues (2013) about what children view as environmental influences on their physical activity. The children blamed the physical inactivity that contributed to childhood obesity in their disadvantaged neighbourhood at least in part on their excessive computer use.

Holloway and Valentine (2000) explored how children make sense of information computer technology (ICT) in their everyday lives by conducting 30 friendship-based focus groups with 11 to 16 year olds at three socioeconomically disparate schools. Home-based interviews were subsequently undertaken with 10 of these students and their parents to explore attitudes toward computers and the internet. The ways children viewed information technology classes were informed by gender and by the status of computers within their local peer cultures. For example, some girls described boys "hogging" the computer terminals during lessons, and told of the strategies they developed with teachers to overcome this barrier to their computer time. The meaning that home computer time had for some boys was shaped by their peer relationships. Boys for whom computer games were a central part of their friendships and identity talked about visiting each other's homes to play computer games and playing on-line games with friends. Holloway and Valentine (2000) explained that the boys' neighbourhood friendships were less reliant on physical proximity and that computer use created the possibility for these boys of "remaining in their own homes but competing against locally-based friends in a virtual environment" (p. 776). By hearing children's views of computers in their everyday lives, that study permitted new

understandings about how children actively negotiated the opportunities as well as the barriers that computer time and the internet created.

In summary, these studies indicate that children perceive home as a setting that offers them more opportunities to exercise agency than school and their mothers as partners for their growing autonomy (Mayall, 1996; Zeiher, 2003). Hearing from children about how they navigate the restrictions placed on their movements made it is possible to learn about how they actively create physical spaces at home and school playgrounds that they designate as their own (Rasmussen, 2004). Studies that present children's perspectives of home and school are relevant to the current study because they provide understanding of the views of children about their mothers and home life that adds to the understanding drawn from the developmental literature. These studies demonstrate that children are agents who can respond creatively to environmental restrictions placed on their freedom of movement and expression.

6.3.3. *Friends in children's intersecting social worlds*

Literature about friendship from developmental psychology presented in Chapter 5 is complemented by research on children's friendships from the sociology of childhood. This perspective makes it is possible to gain insight into how children view friendships and what influences their friendship experiences. Mayall (1996) reported that children viewed school as providing more opportunities than home and neighbourhood to make and strengthen friendships. The children in her study saw school life as centred on food and play, with stories about friends featuring prominently in their accounts of this world and teachers rarely mentioned. Five-year-olds knew that having school friends was important; older children wanted their friendships to be stable and permanent (Mayall, 1996). Hearing about school from

children's points of view makes clear that they see an important function of school to lie in the access it provides to opportunities to form and sustain reliable friendships. This augments an understanding gained from the developmental literature which demonstrated that the children viewed their school experiences primarily in terms of peers and play.

Studies informed by the sociology of childhood about children's perspectives on friends and peers show that their views are shaped by their past experiences and by beliefs about how similar friends and peers are to themselves. Rabaglietti and colleagues (2012) explored how children construct friendships using children's drawings of themselves with a friend. The children who saw their friends as similar to themselves had more friends. Dixon, Murray and Daiches (2012) explored how children viewed the emotional problems of other children. Children were shown vignettes of peers experiencing emotional difficulties and invited to discuss possible causes and their emotional and behavioural reactions. Children drew on past emotional experiences to make sense of the characters' behaviours. Their responses were shaped by the extent to which they held the characters responsible for their behaviour. This suggests that perceptions of culpability play a role in peers' acceptance of children with unusual or difficult behaviour and contributes to an understanding of peer rejection of children with emotional difficulties.

In summary, studies from the sociology of childhood confirm that friends are central to the social worlds of children and that children perceive themselves and their friends to be similar (Mayall, 1996; Rabaglietti et al., 2012). Dixon and colleagues (2012) reported that children feel less sympathetic toward the difficulties of another child with peers if they hold the child responsible for the situation.

6.3.4. *Neighbourhood social worlds*

With their growing mobility, children's engagement with social worlds beyond the home and school increases, and these social worlds are shaped by the physical and social environment and the access to friends and activities that children see as valuable. Scourfield and colleagues (2006) explored how Welsh 8-11 year old children developed an attachment to place using child-centred methods such as maps, cards and sentence completion exercises in focus groups and interviews. Children constructed meaningful categories of people, such as known or unknown, nice or nasty, friend or not friend, whom they associated with particular places. Their attachment to a place was based on the categories of people they associated with that place rather than on characteristics of the place itself. From the children's point of view, cultural categories for places, such as local, national and global, were less important than the attitudes of their social network towards a place.

Hearing children's perspectives about their views of neighbourhoods enables new insights to be gained about differences in how children and adults see neighbourhoods. In a study using child-centred methods such as walking tours and neighbourhood maps to explore how children perceived their neighbourhood, Spilsbury and colleagues (2009) demonstrated that children's neighbourhood maps were different from those of their parents. Children perceived neighbourhoods more positively if they had access to resources such as schools, parks and libraries. Therefore, children had a particular concept of neighbourhood based on their experiences and needs. Milne (2009) asked children about their contact with adults as they moved beyond their neighbourhoods to visit swimming pools, cinemas and the city centre. From the children's point of view, the problems they faced with individual adults and with adult-imposed restrictions, such as those relating to age and "stranger

danger", had the potential to diminish the initial anticipation and excitement they had felt about being able to move into a more public world.

School and neighbourhood playgrounds are prominent features in the everyday lives of children living in urban environments. While it has been suggested that school playgrounds may be viewed by children as environments which deny them opportunities for free and imaginative play (Rasmussen, 2004), playgrounds may also be integral settings for children to participate in physical activity. Willenberg, Ashbolt, Holland, Gibbs, MacDougall and colleagues (2010) observed children at play in school playgrounds and then conducted focus groups with children to understand their experience of this environment. From the children's perspective, changes such as the provision of loose equipment and greater teacher presence in the playground increased their opportunities for physical activity. Karsten (2003) observed children in neighbourhood playgrounds and interviewed them about what affected their playground use. From the children's point of view, whether the playground was tidy and the equipment safe and in good condition influenced whether they wanted to use it.

Studies that explore how children see their neighbourhood when they live in disadvantaged areas can shed light on the influences that shape their everyday experiences, such as perception of safety and opportunities for physical activity (Carvalho, 2012; Mier, Lee, Smith, Wang, Irizarry et al., 2013). Rogers (2012) found that children who lived in a disadvantaged urban neighbourhood had a unique perspective on neighbourhood opportunities and risks. Their social relationships, especially with friends, were critical to their life satisfaction and they consistently named "space" and "friends" as their favourite aspects of the neighbourhood.

Carvalho (2012) reported that children living in disadvantaged neighbourhoods in Portugal wanted more play space, better public space and equipment maintenance, and more security. They were dissatisfied with the lack of playgrounds and damage to the physical environment, such as graffiti on buildings and public equipment, abandoned cars, loud noise, drinking alcohol, violence and conflict on the street. Similarly, Mier and colleagues (2013) explored children's perceptions of environmental influences on their physical activity in severely disadvantaged neighbourhoods. Most children were overweight or obese, and believed that children were physically inactive in their neighbourhoods because they watched too much television or played computer games. These neighbourhoods lacked facilities such as football fields or basketball courts. The children saw physical features of their neighbourhoods, including litter, unleashed dogs, speeding cars and dark streets, as limiting their physical activity. Social features such as fear of gangs and gunshots were also barriers to children's physical activity from their perspective.

Access of children to recreational activities they perceive as important can also be shaped by socioeconomic factors. Children from disadvantaged families were asked about changes in their everyday lives after their mothers became employed (Ridge, 2007). The most prominent changes they reported related to increased financial resources and, in particular, most children noted that there was more money to spend on recreational activities. They reported being able to access clubs, cinemas and other recreational activities for the first time. Davis, Davies, Cook, Waters, Gibbs and Priest (1999) sought children's perspectives of barriers to social inclusion for children from ethnically diverse and socioeconomically disadvantaged backgrounds. From the children's point of view, bullying, time constraints and parental permission were barriers to their social participation. Although only children from English-speaking

backgrounds mentioned financial constraints as a barrier, the authors speculated that children might have been unwilling to divulge their parents' financial difficulties, but that economic factors were likely to have affected parental decision-making.

In summary, these findings underline the value children attribute to having opportunities to play with peers in a safe neighbourhood. With the use of methods appropriate to gaining children's perspectives on their neighbourhood, such as walking tours, differences between the views of children and adults can emerge (Spilsbury et al., 2009). Disadvantaged neighbourhoods can be perceived by children as posing safety risks and lacking appropriate play spaces (Carvalho, 2012; Mier et al., 2013). Gaining an understanding of how neighbourhood risks can shape children's experiences of their social worlds is pertinent to the current study because it is likely that mothers with intellectual disability face socioeconomic disadvantage, as do other adults with intellectual disability (Emerson, 2007). That being the case, their children are likely to live in disadvantaged neighbourhoods, but the implications for their social experiences have not been explored to date.

6.4.   **Conclusion**

Notably, much of the research informed by the sociology of childhood about the social worlds of children has focused on their experiences away from home, particularly at school and in the neighbourhood. This highlights that children see themselves as being very much part of worlds other than home, but that they may see their parents in general and, possibly, mothers in particular as "negotiation partners" with whom they enact autonomy in their daily routines (Mayall, 1996; Zeiher, 2003). In contrast, children may view schools as restrictive environments that limit their autonomy and freedom of movement (Mayall, 1996; Rasmussen, 2004; Willenberg et al., 2012).

Children can actively navigate these restrictions by finding spaces that they can designate as their own (Rasmussen, 2004). Despite the restrictions at school, children see the school context as offering them opportunities to develop friendships that are critical to their sense of personal satisfaction (Mayall, 1996; Rogers, 2012). This literature is important to the current study because it highlights that new and different (and sometimes similar) information about the influences in children's social worlds to that found in the developmental psychology literature can be gained by hearing about children's everyday life experiences from their perspective. The next chapter details the research approach used to conduct this study about influences in children's social worlds from the perspectives of a particular group of children, children of mothers with intellectual disability.

CHAPTER 7: RESEARCH APPROACH

7.1.   Introduction

This chapter describes the research approach used to conduct the study. The study explores children's perspectives of their social worlds in middle childhood, with the aim of understanding influences in the social worlds of children of mothers with intellectual disability. A suitable research approach for this purpose is one that specifically focuses on children's perspectives about their lives.

7.2.   Alignment with theoretical approach

As Chapter 4 outlined, the theoretical standpoint used to conduct the study comes from bioecological theory and the sociology of childhood. The study takes as its starting point the premise that children are a part of their environment (Bronfenbrenner, 1979). It follows that exploration of their social worlds must consider the influence exerted by multiple, intersecting environments. This does not mean that children are passively shaped by external forces. Rather, they are agents who actively create, and can offer credible perspectives on, their social worlds (James & Prout, 1997). Narrative theory explains that it is through the process of storytelling that we construct a meaningful reality (Bruner, 1990). Bruner (1990) argued that narratives align our personal experiences with cultural norms and connect us to the larger stories of our culture. The narratives children tell about their experiences illuminate how they make sense of the world and their place in it (Bruner & Lucariello, 1989; Engels, 2005).

Use of a narrative approach informed by Bruner (1990) is consistent with the sociology of childhood which encourages us to see children as reliable and credible informants about their worlds. A narrative approach is well suited to exploring the

social worlds of children in order to understand the influences on them. Gaining insight into how children in middle childhood see their social world requires a commitment to hearing children's voices through the stories they tell. The study is grounded in research methods that facilitate attainment of this goal.

7.3.   **Narrative research**

In the human sciences, narrative has been defined in diverse ways and through various qualitative approaches (Denzin & Lincoln, 2000; Riessman, 2008; Silverman, 1997). Researchers have explored the narratives of everyday life to answer a broad range of research questions. Narrative researchers have explained the construction and function of narrative in social contexts and the analytic use of narrative models for interpretation (see e.g. Bruner, 1990, 1991; Mishler, 1995; Polkinghorne, 1988; Riessman, 2008). Bruner (1990) highlighted that narratives are embedded in particular cultural, social and historical contexts and that, by listening to the stories people tell, we can gain an understanding about the way they make sense of their lives within these broader contexts.

Appreciation of the varied applications of narrative in human science research creates the possibility that more inclusive approaches to the use of narratives can flourish. With this goal in mind, Mishler (1995) developed a typology of narrative to demonstrate the "depth, strength and diversity of the 'narrative turn' in the many sciences" (p. 117). He identified three types of narrative. The first type links actual events and their textual or discursive representation and is underpinned by a realist perspective that presumes the existence of an objectively "real" sequence of events that can be revealed through analysis. Mishler included narrative life history in this approach because researchers select episodes of people's life story and reorder them

into a chronological sequence which becomes the narrative for further analysis. The focus of the second type of narrative approach is the way individuals construct their story, rather than the chronology of life events told. In this type of narrative, coherence and narrative unity are achieved not through objective patterns of real events but from cultural and linguistic conventions. For example, researchers interested in oral narratives examine communicative functions of speech in different social contexts.

Mishler's (1995) third type of narrative concentrates on the cultural, social and psychological functions of stories: the work they perform, the settings in which they are produced and their effects on storytellers, audiences and wider communities. One approach that Mishler included in this group is the "narrativization of experience" (p. 108). Based on psychological theories of identity, this approach sees the construction of personal narrative as central to the development of the self, and the purpose of narratives as being a means of making sense of temporal experience and personal actions. Bruner's approach to narrative, as described in various sources (Bruner, 1986, 1990, 1991; Bruner & Lucariello, 1989), fits within this third tradition as outlined by Mishler (1995). Bruner's work informs the narrative approach used to analyse the data presented in this study. That approach is now outlined and its use in this study explained.

7.3.1.   *Bruner's approach to narrative*

According to Bruner (1990), narrative is the most ubiquitous form of discourse used in communication and that in all known cultures "we have an urge to narrate ourselves" (p. 138). Bruner explained that the act of constructing a narrative is more than selecting events from real life, memory or fantasy and putting them into an

appropriate order. Memory reconstructions of past events ensure that they align with recognisable narratives and universal stories. In this way, our lives and our experiences of the social world are made meaningful. Like literary narratives, narratives of experience involve an agent who directs the action. They are sequentially ordered and present a narrator's perspective. Like literary narratives, too, they are judged by verisimilitude, not verifiability (Bruner, 1991). Narrative is sensitive to a cultural canon, which means that even unexpected or exceptional plots are rendered comprehensible (Bruner, 1990). Divergent interpretations of reality are negotiated through the use of "a cultural store of narrative resources" (Bruner, 1990, p. 67) including myths, typologies of human plight, traditions and literary devices such as metaphor, trope and metonymy.

As Bruner (1986) pointed out, we tell stories because they give life events a memorable format that makes it easier to understand our personal experiences. However, making existence meaningful by organising it into narrative form operates not only at an individual level; "our sensitivity to narrative provides the major link between our own sense of self and our sense of others in the social world around us" (Bruner, 1986, p. 69). Bruner (1990) argued that we reach a cultural consensus about how the world works by sharing narratives that conform to shared cultural beliefs. According to Bruner (1990) narrative renders individual experience meaningful in such a way that it is compatible with these other shared stories. In spite of what Bruner (1986) described as the "irreducible plurality of worlds" (p. 98), he acknowledged that there are not endless different narratives, but similar stories that are told across cultures and over time. Bruner (1986) explained that this is because a shared cultural canon enables us to accommodate different truths by treating them as versions which are true in different worlds (Bruner, 1986). As Bruner (1990) pointed

out, a breach in the expected course of events is a necessary precondition for narrative construction, because "when things 'are as they should be', the narratives of folk psychology are unnecessary" (p. 40).

According to Bruner (1990), narrative enables us to understand what people say their worlds mean. His approach to narrative is underpinned by the belief that social worlds are constituted by the stories we tell about them. This makes it a useful approach to understanding children's social worlds. Narratives are commonly made for an audience and serve to construct a version of experiences that can be understood not only by the person who experienced them but also by others. We interpret our experiences of social worlds in ways that make sense within our own particular contexts and which are meaningful to others, within a broader historical and social context. Guided by this approach, I argue in this thesis that the social worlds of children of mothers with intellectual disability, children, can be understood by interpreting those children's narratives.

7.3.2. *"A predisposition to contrive the social world": Children and narrative*

Bruner (1990) explained that we are born with "a predisposition to contrive the social world in particular ways and act upon those contrivances" (p. 73), which he called a primitive form of folk psychology. Being able to tell and interpret narratives about life "lends stability to the child's social life" (Bruner 1990, p. 68) by giving shape to an otherwise formless and incomprehensible tangle of experiences. The push for children to construct narrative even determines the way in which they master grammar. Children learn to make sentences in subject–verb–object order, which Bruner (1990) described as "somebody does something" (p. 79), and according to temporal

orientation of the past, present and future. As soon as they can use language to name things, children become interested in human action and its outcomes.

Telling stories enables children to make fundamental distinctions in how they organise reality. Bruner and Lucariello (1989), for example, analysed the bedtime stories a toddler told herself in which she organised that day's experiences into things that normally happen, possible events and things that are unusual or exciting. This demonstrated that even young children experiment with distinguishing the canonical from the non-canonical and, in this way, the narrative form constructs experiences. Even young children understand that their actions are interpreted not solely on the basis of actions themselves but also on how these actions are explained for themselves and others (Bruner, 1990). Children tell stories not only as a way of reporting on events that happened in their everyday lives but also to make sense of these experiences (Bruner & Lucariello, 1989). The purpose of telling stories is to record one's own perspective on events and persuade others that that is the most reliable version (Bruner, 1990). Listening to their own interactions recounted by another makes children aware that acts are less important than their interpretation and, by implication, that narratives always serve a particular interpretation.

7.3.3. *Using Bruner to interpret children's narratives*

Bruner (1990) made clear that cultural, historical, social and familial contexts influence the narratives children construct to represent their experiences. Informed by Bruner's work, researchers from within and beyond his developmental paradigm have undertaken narrative studies to understand children's everyday lives. The dimensions of children's narrative skills and the factors influencing their narrative competence have been investigated. Studies have linked the strength of childhood memories to the

sophistication of the narratives children create about past events (Van Abemma &
Bauer, 2005). Differences have been found in the sophistication and frequency of
children's narratives depending on their age (Sperry & Sperry, 1996) and on whether
the narratives are associated with wordless storybooks or personal experiences (Losh
& Capp, 2000). Differences have also been identified in the narratives of children with
autism and Asperger's Syndrome (Losh & Capp, 2000) and acquired brain injury
(Spiddle, 1996). Children's narratives have been analysed to determine the reliability
of their recollections of past sexual abuse (Lamb & Brown, 2000) and their
suggestibility to being misled by adults (Kulkofsky & Klemfuss, 2008). In a large
study investigating whether preschool-aged children's memories of past events are
susceptible to suggestibility by adults, Kulkofsky and Klemfuss (2008) found that the
likelihood of children falsely assenting to misleading questions about an event was
decreased when children provided a high-quality narrative of that event.

Bruner (1990) explained that telling stories creates memory reconstructions of past
experiences. Following Bruner, Engels (2000) argued that the more able children are
to use stories in social interactions, the more these interactions come to shape their
representations of their experiences. In a study investigating the narrative ability of
very high-functioning children with autism and Asperger's Syndrome, Losh and Capp
(2000) found that they had difficulty independently producing thematically integrated
and elaborated narratives of personal experience, which limited their access to a rich
form of interaction. By homing in on specific experiences for narrative formulation,
selecting and discarding particular events for recollection, children actively create
their social worlds.

Engels (2000) proposed that the action of telling a story is one way children negotiate the boundaries between inner and outer life and that the form of their narratives reveals their concerns and how they organise the world. Engels (2005) explained that storytelling enables children to solve emotional puzzles, affirm friendships, construct and communicate a self and participate in culture (p. 206). She claimed that no storytellers, whether adult or child, are necessarily aware of what concern is being expressed in their story or what purpose the story fulfils (Engels, 2005). While children's stories may reveal something about the puzzles that shape their everyday experiences, it does not follow that a child consciously experiences them as puzzles. The significance can be deduced through analysing their narratives as is the case in the current study. The following chapter describes the methods used for data collection and analysis.

CHAPTER 8: RESEARCH METHODS

This chapter describes the methods employed to conduct the study. Semi-structured interviews and creative tasks were undertaken with seven children of mothers with intellectual disability in order to address the research questions that drove the study. That is, to understand the particular influences that shaped their social worlds and the potential influence of a restricted social context for mothers with intellectual disability on the social worlds of their children. Participant selection was informed by the definition of intellectual disability and terminology used for recruitment purposes as detailed in the next section.

8.1.   **Recruitment**

8.1.1.   *Definition of intellectual disability*

To recruit children to the study, I used a social systems definition of intellectual disability to identify mothers with intellectual disability. Experts in the field agree that most parents labelled with intellectual disability have mild to borderline cognitive limitations (IASSID SIRG on Parents and Parenting with Intellectual Disability, 2008). Many of these parents would not meet a clinical criterion for diagnosis of intellectual disability and may not use disability services, making this an unlikely recruitment source. I needed to use a definition of intellectual disability that enabled identification of mothers who might not use disability-specific services but who were seen by significant others in their lives as having intellectual disability. The social systems definition of intellectual disability developed by Mercer (1973) was used.

Mercer (1973) argued that taking a biological or a rigid intelligence quotient (IQ) perspective of intellectual disability views individuals in isolation rather than as part of their social context. The social system perspective, on the other hand, stems from a

132

sociological tradition in which the term "normal" does not imply particular behaviour with an inherent value but simply describes the performance of roles that conform to social expectations. According to Mercer, intellectual disability refers to the label applied to a person who occupies a particular role in the social system. It follows that if others do not regard the person as having intellectual disability then, regardless of their IQ, adaptive behaviour or the extent of organic impairment, they do not. A social systems definition permits researchers and service providers to identify people with intellectual disability by reference to significant others in the social system including family members, schools, hospitals, disability services and other agencies. In this study, I applied the social systems definition of intellectual disability by asking mainstream child and family services, specialist parenting services and a professional contact from the intellectual disability field to identify mothers they regarded as having intellectual disability or learning difficulties.

As explained in Chapter 3, the terminology used internationally to describe intellectual disability has changed over time. In Australia, "learning difficulty" is now widely used by services working with parents with intellectual disability (see e.g. www.healthystart.net.au). This term is consistent with a social systems definition and was used for recruitment purposes in recognition of its familiarity in the Australian context (McConnell et al., 2008) (Appendix F).

8.1.2. *Convenience method*

The literature review about children of parents with intellectual disability included in Chapter 3 (Collings & Llewellyn, 2012) demonstrated that researchers typically recruit children of parents with intellectual disability using convenience methods where mothers have come to the attention of researchers through their involvement

with specialist parenting services for parents with intellectual disability or mainstream child and family support services.

Along with recruitment from these sources, I also recruited children whose mothers were not engaged in those services. Feldman (1997), a prominent researcher in the field of parenting with intellectual disability, noted that mothers whose parenting skills and support systems are adequate may never come to the attention of services. In light of Feldman's comments I approached a professional contact whose work within the intellectual disability advocacy field brought her into contact with mothers with intellectual disability, including those not engaged with the service system.

I present the convenience method used in this study as three distinct, non-sequential, overlapping strategies used to maximise recruitment opportunities. Middle childhood, in the Australian context, is associated with the period when children attend primary school, typically between 6 and 12 years of age (Collins, 1984; Cooper et al., 2005; Huston & Ripke, 2006). Recruitment commenced in July 2010 and ended in March 2012.

8.1.3. *Strategy 1: Mainstream child and family services*

In July 2010 I contacted personnel from a child and family support agency in New South Wales (NSW), who agreed to recruit children through their mainstream services in South West and Outer West Sydney, two metropolitan areas of Sydney.[4] From estimates of potentially eligible families the agency personnel anticipated they could

---

[4] The combined population of these regions in 2011 was 634,186 (Australian Bureau of Statistics, 2012). According to the Socio-Economic Indexes for Areas (SEIFA), South West Sydney was the most socioeconomically disadvantaged region in Sydney in 2011 (Australian Bureau of Statistics, 2011).

facilitate the recruitment of up to 20 children. Written information about the study was sent to service managers working at the regional office (see Appendices B, C, F). I met with a team of caseworkers[5] from their child and family services and distributed consent materials and answered questions about the study, their role in recruitment, and what participation would mean for the mothers and their children. As outlined later in this chapter, the study involved children taking photographs prior to their first interview. Camera protocols were outlined in written information about the study and verbally explained to the children by the recruiting agency. For the following 6 months I maintained regular contact with these managers and caseworkers but received no referrals for potential participants. At that time, one of the service managers explained that the agency currently worked with fewer mothers with intellectual disability than they had anticipated. They agreed to review all caseloads and this resulted in the recruitment of two children by the end of the recruitment phase.

In January 2011, I contacted two organisations whose members included mainstream child or family services. The first, the Australian Research Alliance on Children and Young people (ARACY) (www.aracy.org.au), has over 2000 members that are nationwide organisations and individuals in the research, policy and service sectors, as well as government personnel, advocacy bodies and other community contributors. The second organisation, NSW Family Services (www.nswfamilyservices.asn.au), is a peak organisation of non-government services supporting families experiencing stress in over 300 service outlets across NSW. Both organisations agreed to promote the

---

[5] Caseworker is a generic term used in this thesis to describe a staff member working directly with a mother with intellectual disability and her children.

study to their members, and advertisements appeared in electronic newsletters circulated to their members during 2011 (see Appendix F). By the end of the recruitment phase no agencies had made contact.

8.1.4. *Strategy 2: Specialist parenting services*

In September 2010, I approached *Healthy Start: A national strategy for children of parents with learning difficulties* (www.healthystart.net.au) regarding recruitment and they agreed to promote the study through their member networks. *Healthy Start* is a Commonwealth Government funded initiative operated by the Australian Supported Parenting Consortium[6]. *Healthy Start* aims to build the capacity of services working with families headed by parents with intellectual disability around Australia through the provision of knowledge-exchange opportunities to develop evidence-based, best practice approaches (see McConnell et al., 2008 for a description of this strategy). Members represent individuals and organisations working with parents with intellectual disability. Information about the study appeared in two *Healthy Start* monthly electronic newsletters which were sent to over 2000 individuals or organisations, and flyers promoting the study were distributed at *Healthy Start* training sessions and member forums around Australia (see Appendix F). In November 2010, a member organisation from rural New South Wales facilitated the recruitment of one child the study. In July 2011, I promoted the study at a *Healthy Start* National Forum and sought permission to contact conference delegates afterwards. As a result of personal contact via email with sixty *Healthy Start* members, five mothers from three Australian states consented to their children taking

---

[6] A partnership between the Parenting Research Centre and the Australian Family and Disability Studies Research Collaboration at the University of Sydney (www.healthystart.net.au)

part in the study. However, none ended up participating in the study, for the following reasons.

1. A Queensland-based agency recruited two brothers to the study, but the caseworker was unaware that the older child was not eligible to participate as he had spent most of his life in out-of-home-care and had only recently returned to live with his mother. The older sibling withdrew from the study shortly after the interview began and his younger brother, who had initially agreed to be interviewed, declined to participate any further. The interview data for these children is not included in the study.

2. A specialist disability service in New South Wales recruited a child, but several attempts to schedule an interview proved unsuccessful when the mother was unable to commit to a time or was dealing with a family crisis. After several months she withdrew consent.

3. A Victorian agency recruited two children but immediately prior to the interviews one mother withdrew consent and a child from a second family decided not to participate.

4. A disability service in Victoria recruited the child of one of its clients but the mother and child failed to attend the scheduled interview. When I contacted her, the mother she explained she had changed her mind. The reason given was that her mother feared that if the child portrayed the family in a negative light by the child it might lead to scrutiny by child protection agencies.

8.1.5.   *Strategy 3: Professional contact*

In July 2010 I met with a professional contact involved in advocacy for people with intellectual disability. I explained that I hoped to create opportunities for children of

non-service-using mothers to participate. My contact explained she knew of two such mothers who had school-aged children. She approached them about the study, providing identical written information about the study as the other families had received. Both mothers gave consent and all four children (two sets of twins) gave verbal assent.

8.1.6. *Recruitment barriers*

In summary, three main barriers to recruitment were encountered. The first was children not meeting selection criteria. This happened because several mainstream child and family services I contacted explained that the families headed by parents with intellectual disability with whom they were engaged were those who had pre-school aged children, as they were associated with early intervention programs such as Brighter Futures which prioritise families with children under three years[7]. The second potential recruitment barrier encountered concerned the role of child protection services in these families. I was informed on several occasions by parenting services for parents with intellectual disability that the mothers they worked with had school-aged children who had been removed from parental care, and thus were not eligible to participate. Moreover, some specialist parenting services raised the possibility that mothers with intellectual disability might be reluctant to let their children participate for fear of scrutiny by child protection services. As noted, one mother used this explanation for withdrawing consent. It is not possible to determine the extent to which the fear of child protection or child removal was a recruitment barrier.

---

[7] For the Brighter Futures program evaluation, see Hilferty *et al*., 2010. Parental intellectual disability is identified as a specific vulnerability for eligibility to the program (www.community.nsw.gov.au).

The third potential barrier encountered in this study was navigating adult gatekeepers to recruit children. Recruitment involved engaging with managers or caseworkers, not directly with the mothers. Hood (1996) argued that professional "gatekeeping" is a form of adult social control over children's participation in research; Dockett and Perry (2011) made the point that recruitment negotiations with managers in service agencies and organisations such as schools precede contact with parents, let alone their children. Hood argued that staff might view it as part of their role to evaluate the merits of participation in research on behalf of parents, describing a "hierarchy of gatekeeping" (p. 121) as operating in the recruitment of children through organisations. Formal services were involved in the recruitment of five children[8] over one year and three examples of gatekeeping were encountered: 1) a service manager stated that the service which employed him did not work with mothers with intellectual disability, despite the agency having previously facilitated the recruitment of two children to the study; 2) a caseworker refused to approach a mother because she believed she was unlikely to consent; and 3) a caseworker expressed concern that a child's participation in the study would deflect attention from the casework she was undertaking with his mother.

8.2. **Interviews**

Each child was invited to take part in at least two interviews to explore whether there were changes to their lives over time. The time that elapsed between the first and last interview differed for each child, with a range from 3 to 11 months. Variation was due to factors such as travel and family availability. Written information provided to children and their mothers explained that children would be given a disposable camera

---

[8] Including two brothers who withdrew from the study

to photograph people, objects and places that were important to them (see Appendices B, E). They were advised that their photographs would be returned to them at the first interview. The use of photographs as a research activity is discussed later in this chapter.

8.2.1.   *Ethical consent processes with children*

Morrow and Richards (1996) pointed out that the legal requirement to obtain consent from a child's parent or guardian presents an ethical conundrum for child researchers, particularly those informed by the sociology of childhood. Morrow and Richards argued that, given a broad social context in which children's ideas are routinely trivialised, it follows that their consent is not assumed to be essential to the research process. In Australia, children are not legally able to provide informed consent to participate in research. The National Health and Medical Research Council's (NHMRC) (2007) ethical guidelines for research with children and young people do not identify an age at which children and young people become capable of providing informed consent but note that a child should give "specific consent ... whenever he or she has the capacity to make this decision" (p. 55).

An additional process whereby children can exercise choice about participation used by child researchers is assent. According to Dockett and Perry (2011), assent is an agreement obtained from those who are not able to enter into a legal contract. Dockett and Perry favour seeing assent as provisional, such that researchers continuously renegotiate ongoing assent with children during the research process. Children's assent, viewed as relational and provisional, can be deduced by observing nonverbal cues and body language. In line with the position on informed dissent taken by Morrow and Richards (1996), Dockett and Perry (2011) made the point that

involvement must be based on an active decision to take part, and children need accessible and appropriate information about the research to make an informed choice.

Two ethical considerations in relation to participant consent were relevant in the current study. The first was that mothers with intellectual disability were able to give informed consent on behalf of their children and the second was that the children were given a say in the decision to participate. In recognition that mothers with intellectual disability might have limited literacy or difficulty comprehending verbal explanations, the consent process incorporated steps to ensure that consent was informed by clear understanding of what participation involved. As well as written information (Appendix B), the study was verbally explained to the mother by a familiar person such as a caseworker or family member. Following consent, mothers were asked to complete a questionnaire to confirm informed consent (see Appendix C, D). Children were given separate written information explaining the purpose of the study and what participation would involve (Appendix E). Children's verbal assent was obtained when their mother granted written consent and was viewed as provisional. Thus, at the start of each interview, children were reminded that their participation was voluntary and asked to confirm that they still freely chose to take part.

8.2.2.   *Conducting interviews with children*

Harden and colleagues (2000) suggested that the artificiality of the interview environment is likely to be heightened for children by unequal adult-child power relations. Others have noted that children are not used to being asked to relay their opinions to unknown adults because they are accustomed to adults speaking for them in a variety of everyday contexts (Balen et al., 1996; Harden et al., 2000; Morrow & Richards, 1996; Westcott & Littleton, 2005). According to Mayall (2000), underlying

power differences cannot be ameliorated in interviews but researchers can take steps to make the interview process less intimidating. Therefore following Westcott and Littleton (2005), I approached the interview as a "co-constructive process of meaning-making" (p. 153) and chose methods recommended to be more likely to empower children to talk about their experiences.

According to Morrow and Richards (1996), interviewers who spend time familiarising themselves with child participants can reduce their anxiety and discomfort and make it easier for them to give an account of their experiences, beliefs and feelings. Dockett and Perry (2011) argued that this is particularly helpful for engaging children who are less verbally articulate or less willing to engage in verbal interactions. Familiarity makes it possible for a researcher to gauge a child's interest and comfort with participation (Dockett & Perry, 2011). Consequently, I arranged to meet the children if possible before the first interview to explain what participation involved and give verbal guidance about the use of a camera, a creative task used in the study. Time constraints and physical distance prevented me meeting two children beforehand but I set additional time aside to talk with these two children informally before their first interview, and in the presence of a familiar adult.

Guided by a suggestion from Danby and Farrell (2005), I set an informal tone for the research conversation at the start of each child's first interview. I spent between 5 and 10 minutes outlining what would happen during the interview and reminding children that this would be an informal conversation with no wrong or right answers. I asked each child whether he or she still wanted to take part and reminded them to request a break any time, to say if they wanted to stop talking or simply leave the room. I showed each child how the recording device worked and explained that using it would

enable me to focus on our conversation rather than make notes but that I would only use it with their permission. All children agreed for their interviews to be recorded. I presented children with the photographs they had previously taken and turned on the recording device to commence the interview.

At the second (and, in some cases, third) interview I found that children checked that I remembered our earlier discussions. Between interviews I reviewed earlier transcripts to recall details of our discussions and made notes about topics that were most important to them and noted topics not yet discussed. Having more than one interview was particularly important with children who engaged less openly during their first interview. For example, two children terminated their first interviews relatively quickly but at two subsequent interviews they were noticeably more talkative and each of these interviews lasted over an hour.

8.2.3. *My role as interviewer*

It is recognised that interviews with children require some additional techniques to overcome potential barriers posed by generational power differences. Child researchers have experimented with different ways to build rapport with children, including adopting the position of "least adult" (Mandell, 1991) or researcher-as-friend (James, Jenks & Prout, 1998). Other researchers are critical of these tactics, arguing that they could backfire and make children suspicious and uncomfortable with a researcher (Harden et al., 2000). Mayall (2000) proposed that researchers work within the generational issues implicit in adult-child relations by accepting that adult power over children cannot be diffused in an interview context but adults can resist assuming *a priori* adult superior knowledge.

I followed Mayall's approach by asking children about their everyday lives, knowing that this was likely to be a comfortable topic about which they were the experts. In using this approach I was acknowledging that, as an adult, I could not know what it meant to be a child today and needed their help to understand childhood from children's perspectives. Secondly, I saw them as experts about their own lives, who were in the unique position of describing the particularities of their experiences. By wearing casual clothing I made an effort to ensure that my appearance reinforced the casual and informal tone I wanted to achieve. Harden and colleagues (2000) suggested that researchers show an interest in children's interests and share information about themselves to build a connection with children. I was attentive to each child's level of comfort with the interview, for example noting if a child avoided or maintained eye contact and mirroring this preference. Learning about a child's passions enabled me to find points of authentic commonality when we shared a similar interest or I could demonstrate knowledge about their interest. For example, I was able to offer an opinion about a cartoon hero that a child expressed an interest in by explaining that my children shared his interest and this forged a point of connection between us.

8.2.4.   *The location of interviews*

Where to interview children is contentious. For example, Morrow and Richards (1996) argued that interviews conducted at school could make it harder for children to dissent because school is associated with compulsory tasks, yet Hill and colleagues (1996) suggested that children might communicate less openly at home because they are conscious of the presence of family members. In contrast, Dockett and Perry (2011) argued that children feel more comfortable talking to researchers when familiar adults are nearby. Other researchers have suggested that the observed variations in children's responses to specific interview settings come down to individual

differences such as temperament (Hood et al., 1996), gender (Hill et al., 1996) and other personal attributes (Greene & Hill, 2005). Building on this knowledge, I chose to follow the suggestions made by people most familiar with each child. So, for the children recruited through formal services, following the caseworkers' suggestions, the first interviews were held at their office. Children recruited through a professional contact were first interviewed at their own home (boy twins) and their godmother's home (girl twins).

For the second interview I asked the children and their mothers what they would prefer. As a result, interviews were held in a combination of public and private spaces, including a child's bedroom, a public common area, a park, a beach, a cafe, and a library (see Table 3). Some locations were easier than others. For example, I found it somewhat difficult to converse with the twin boys while walking along a beach, but neither child asked to terminate the interview as they had done previously.

8.2.5.   *Ethics*

The Human Research Ethics Committee (HREC) at the University of Sydney approved the study (Number 07-2008/11006). Approval details, together with written information regarding recruitment procedures for services, participant and parent information and consent materials, an informed consent questionnaire and the interview guide are included in the appendices A-H.

8.3.   **Research activities**

It has been suggested that engaging children in task-centred or creative research activities can enable them to express their ideas and opinions more easily than structured formats such as interviews or questionnaires (Christensen & James, 2000; Greene and Hill, 2005; Veale, 2005). However, Harden and colleagues (2000) warned

researchers not to presume that creative techniques can reveal some truth not accessible through talk and caution researchers to avoid reading meanings into children's creative productions which may not be there for the children themselves. In this study, I used three research activities: open-ended semi-structured interviews, photography and drawing. The two creative activities supplemented the semi-structured nature of the interviews and creative productions were used solely in interviews and were not analysed as specific research artefacts. Although the drawings and photographs were not analysed as creative productions they were a source of data in that they provided another medium through which a child could tell their story about, for instance, the important people in their lives. As such, drawings and photographs produced interview data that was included in the analytic process used to create the individual narratives and family profiles. The next section explains the reasons for using each of these activities. Table 3 details each child's activities. Names used are pseudonyms.

Table 3: Research Activities

Name of activity	Description of activity	Details (instructions, materials, discussion topics)	Who completed activity	Reason for non-participation
Photography activity (part 1)	Take photographs of things, people and places a child views as important to them	Provided disposable camera with verbal or written instructions for use and then developed film prior to interview	Damien, Harrison, Michael, Olivia, Simon	Mia and Rosie were unable to complete either activity components because their cameras were not functioning
Photography activity (part 2)	Create and decorate a photo album in an interview	Provided small photo album, decorative stickers and adhesive labels	Harrison, Michael, Olivia, Simon	Damien had only three photos of sufficient quality to be visible and did not make an album
Semi-structured interviews	Participate in at least two guided interviews at two points in time.	1. Me and my family, 2. My role in my family 3. Who helps me 4. School 5. Friends 6. Where I live	Damien, Harrison, Mia, Michael Olivia, Rosie, Simon	Harrison, Michael and Simon took part in a third interview due to an earlier interview being interrupted
Drawing activity	Draw a social relationships diagram depicting the people in the child's life	Provided a large sheets of white paper and crayons and gave verbal instructions	Damien, Harrison, Mia, Olivia, Rosie	Michael and Simon chose not to take part in the activity
		Invited children to undertake free drawing as they chose	Damien, Harrison	Five children chose not to do free drawing

8.3.1. *Open-ended questions, semi-structured interviews*

This study used a purpose-designed interview guide structured around the insights gained from bioecological theory about the interaction between children and their environment (Bronfenbrenner, 1979; Bronfenbrenner & Ceci, 1994) (see Appendix G). Four social contexts in children's lives formed the basis for the interview guide.

1. Family was explored in two topics: "me and my family" and "my role in my family", which concerned relationships, roles, everyday tasks and self-view. A related topic of "who helps me" explored the role of other significant adults.

2. School was explored in discussion about what children liked and disliked about school.

3. Peers were explored in discussion about friends, bullying, activities, and positive aspects or issues in their friendships.

4. Neighbourhood was explored in the topic "where I live".

The guide introduced these topics through open-ended questions related to each topic to enable each child to decide what direction to take the discussion and to interpret the topics as she or he chose.

8.3.2. *Photography*

Each child was given a disposable camera before their first interview and asked to photograph "things, people and places that were important to you" (see Appendix E). Using photography in interviews has become popular over recent decades and is known as Photovoice (Wang & Burris, 1997). Child researchers (Orellana, 1999; Morrow, 2001; Strack et al*., *2004) have argued that photovoice is an empowering research tool for use with children and young people and is capable of informing policy and programs to address children's needs. Three examples come from first

Clark (1999) who invited young children to take photographs to depict their personal experience of chronic illness as a complement to semi-structured interviews; second, Morrow (2001) who explored young people's views of their social environments through their photographs of places they regarded as important; and third Shannon (2013) who asked young men who had been recently released from juvenile detention to photographs their everyday lives as a way to gain understanding of their needs.

According to Harden and colleagues (2000), photographs and other task-centred research activities can be a "time out" from the intensity of maintaining eye contact for children and, as with the study by Clark (1999), photographs taken by each of the children operated as a conversational stimulus in this study. Returning a child's photographs at the start of their first interview provided an immediate conversation focus for the five children whose cameras were able to be used. Two children were unable to use their camera and brought photographs from their personal collection to the second interview. Together with a third child who was only able to take three photographs of sufficient quality for discussion, these three children were unable to create a photo album. Five children accepted my offer to take home a second camera (see Table 4, p. 165).

8.3.3. *Drawing*

The drawing task was designed to allow children to depict their social relationships as a series of concentric circles. I call this activity a "social relationships diagram" building on Bronfenbrenner's (1979) description of a child's environment as a nested structure comprised of multiple contexts. I used the social relationship diagram activity as a complement to the guided interview which focused on the four main social worlds for children. At one of their interviews, each child was invited to take part in a drawing

activity and five children accepted. I laid out a large sheet of white paper and coloured crayons at a table or on the floor. Children who did this activity were asked to draw four concentric circles and, with their own name in the centre, to put the names or initials of people whom they see more or less regularly and felt more or less close to, in the circles around them. I also asked all the children to draw at any time during the interview and advised them that the crayons and their drawings were theirs to take home. Two children chose to draw during the interview and one spent much of the interview engaged in drawing. The activity itself became a conversation piece.

8.3.4. *Recording and transcripts*

I recorded all interviews using a digital recording device from which I could create a verbatim written transcript of verbal interactions. A transcript was completed shortly after the interview to maximise my recall of the nonverbal interactions that had taken place. Whenever nonverbal gestures such as head-shakes, nods and shoulder shrugs were recalled, a notation was made on the written transcript. This meant that gestures were considered in the context of the topic under discussion at that time. The transcript also noted when the recording device had been turned off and why, when a child moved around, when someone entered the room, or interrupted the interview. This was particularly relevant when interviews took place at a child's home.

8.4. **The sample group**

Nine children between 7 and 11 years of age were recruited. Two children withdrew from the study prior to or during their first interview and therefore are not included. Seven children from five families participated, including two sets of identical twins. The participants were four boys and three girls aged between 7 and 10 years of age at

recruitment. Six children lived with a single mother and one child lived in a two-parent

family. Table 4 provides details about recruitment and interviews.

Table 4: Interview contexts

Name	Recruitment source	Age at first interview	Consent process	Camera process	Interviews month	Interview locations	Time lapse from first to last interview
Damien	Disability service	10 years 10 months	November 2010: Service obtains parental consent	December 2010: camera mailed to service and delivered to child	January 2011	Disability service office	10 months
				January 2011: camera returned for development	November 2011	Local park, driving around town	
Harrison	Family support service	9 years	September 2011: service obtains parental consent	September 2011: camera mailed to service and delivered to child	September 2011	Family support service's office	3 months
				Service develops film before interview	November 2011	Private room at local library	
					December 2011	Family home	
Mia	Professional contact	7 years 8 months	October 2011: researcher meets family to obtain parental consent and child assent	October 2011: researcher provides camera; film unable to be developed	October 2011	Godmother's home	5 months
					March 2012	Family home	
Michael	Professional contact	9 years 5 months	October 2010: researcher meets family to obtain parental consent and child assent	October 2010: researcher provides camera; collects completed film, develops before interview	November 2010	Family home	11 months

					January 2011	Public common area	
					October 2011	Walking along the beach; car; cafe	
Olivia	Family support service	8 years			January 2011	Family support service's office	10 months
					November 2011	Family home	
Rosie	Professional contact	7 years 8 months	October 2011: researcher meets family to obtain parental consent and child assent	October 2011: Researcher provides camera; film unable to be developed	October 2011	Godmother's home	5 months
					March 2012	Family home	
Simon	Professional contact	9 years 5 months	October 2010: researcher meets family to obtain parental consent and child assent	October 2010: researcher provides camera; collects completed film, develops before interview	November 2010	Family home	11 months
					January 2011	Public common area	
					October 2011	Walking along the beach; car; cafe	

8.4.1. *Getting to know the children*

Following Bruner's approach to narrative, an individual narrative was created for each child and then family profiles were compiled from interview data and supplementary information from parents and formal services. Profiles should be read as a companion to the individual narratives in that they provide a context for understanding a child's social worlds at the time of the study. The children's profiles and individual narratives are presented in alphabetical order based on their given names. In the case of the two sets of twins, the order is based on the given name of the child who appears first in the alphabet (so that the twins' profile and narratives are presented together). Profiles and narratives are included as appendices (See Appendix H).

Family profiles

A profile was compiled to describe the current social contexts for each child. The profiles include details about family members and other significant adults, living arrangements, school, friends and everyday routines. Bioecological theory (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 1998) positions children at the centre of their social worlds and it follows from a bioecological standpoint on child-environment interactions that the most immediate settings exert the greatest influence on children's lives. The profiles were constructed with this in mind.

Profiles were constructed using two main sources. In recognition that children are reliable informants about their lives, the primary source was interviews with the children. Consistent with a research approach informed by the sociology of childhood that sought children's perspectives about their social worlds, the major data source was the interview material from the children. However, supplementary sources of information became available from family members and, in some cases, caseworkers

working with a family. The decision to incorporate information from supplementary sources was not taken lightly, given my declared trust in the accuracy and reliability of information provided by children. Through contact with family members and caseworkers, however, new information that contributed to a developing picture of the social context of a child was sometimes offered. Information was only included if it clarified something that a child alluded to or shed new light on an aspect of the social world that was central to the child's narrative but which otherwise remained obscure or inexplicable. For example, at her first interview Olivia expressed frustration about her lack of social participation. Ten months later her mother disclosed to me that she had been suffering from serious depression but had recently commenced medication that improved her symptoms. At the second interview, Olivia talked excitedly about after-school activities she had commenced. Knowing about her mother's improved mental health provided a context for understanding this change for Olivia.

Individual narratives

This thesis contends that childhood is constructed through social interactions that take place within a specific social, cultural and historical context. As agents in their social interactions, children actively shape their social worlds and have a unique perspective on their lives. Following Miller and Glassner (1997), I argue that "narratives that emerge in interview contexts are situated in social worlds ... that exist outside the interview itself" (p. 105). The stories children told me in interviews helped to explain the way they viewed their social worlds. Individual narratives constructed from these stories could therefore shed light on influences that shaped the particularities of their social worlds. The narratives are loosely structured around the four main topics in the

155

interview guide (family, school, friends and neighbourhood), corresponding to the four social worlds that are the focus of this thesis.

Individual narratives were constructed from the responses children gave to interview questions and from our discussions as they talked about their photographs, their social relationships diagram, or engaged in free drawing. I use the term "co-construction" to describe the process whereby these narratives were created by a teller and an audience together, in a specific context and for a particular purpose (Hall & Powell, 2011; Riessman, 2008). The context in which children shared their stories was the company of an adult researcher during an interview, and this context inevitably shaped the stories they told. I also contributed acts of narrative construction by being the researcher who transcribed their words, interpreted their meaning and crafted these words into a narrative form for analytic purposes. As Riessman (2008) explains, a researcher's "prior texts"—their beliefs, experiences and concepts —determine what they see as they compose the interview transcript (p 32).

Individual narratives were created to depict how the children represented their social worlds over time. In recognition of the influence of time on children's social worlds, I begin each narrative with an introduction to the context in which the each interview took place. This includes such aspects as the physical environment and people present, the time that elapsed between interviews and major changes that had taken place during this time.

Children's stories were told in response to different research activities. For example, the interview guide topic of friends led Olivia to tell a story about a friend rejecting her party invitation and a discussion about a photograph prompted Mia to share a story about her godmother coming to the rescue of her drowning twin. Harrison's story

about his ambivalent relationship with his brother emerged over several conversations, including one prompted by his social relationships diagram in which he explained that he did not want to include a family friend in the diagram because he bullied his brother. This example also highlights the point that some stories were presented in their entirety at one point in time whereas others, like the story of Harrison's relationship with his brother, emerged over one or more interviews. I connected these linked sequences of events or story fragments by closely re-reading each child's interview transcripts. This was also the case when several distinct story vignettes which were not chronologically linked in an interview were later found to share a narrative thread. For example, Simon's narrative included many stories about his mother's efforts to create a safe home for him, such as a story about her seeking help to find housing from formal services and leaving one home because of burglary and another due to domestic disputes.

Stories achieve narrative continuity and coherence by the context and the purpose for which they are told (Riessman, 2008). In constructing individual narratives I have been mindful not to silence contradictory or inconsistent stories. As Bruner (1990) argued, narratives are immune to claims of truth or fiction. It is worth noting that temporal and contextual factors make narrative inconsistencies possible and that these are not seen as undermining narrative integrity but as an inevitable element of all storytelling, especially that which relies on memory reconstructions. Discrepancies are unsurprising when children relay events that took place before they were born or in early childhood, as their accounts of such events are based on stories told by others, heard and then retold by the child.

In the process of co-constructing children's narratives from interviews there is a risk that the voices of the children themselves may disappear (Danby & Farrell, 2005; Hill, 2005; Roberts, 2000). I employed specific techniques to minimise the risk of children's voices being obscured. Following Bruner (1990), I favoured close study of the language children used to make sense of their own and others' motivations, expectations and memories, which include revealing words, signature expressions and tell-tale grammatical forms.

A technique I used to draw attention to children's personal language style was to use extended direct quotations to bring their voices to life. I achieved this by extracting stories children told about a topic, person, place or event from their transcripts and arranging those stories to form a coherent narrative sequence, with my words inserted at times to achieve this. As people often speak in incomplete sentences, verbal exchanges can lack the grammatical accuracy of the written word. Verbatim quotes from children can be difficult to read at times because children often speak in short or unformed sentences. I inserted linking words to preserve narrative flow and differentiated them from the children's words by the use of brackets. I added my words when quoting an exchange in which the child's response to a question made no sense without reference to the question. For example, when asked who was the person he was closest to Damien responded "mum is" so I inserted the words (the person I felt closest to) in brackets to construct a meaningful sentence. I also inserted my words in brackets to locate an event in time and place and to ensure that the narratives were logical. For example, when Simon described an event that precipitated a house move I added the words (After that, mum went to this place) to provide a logical chronology of events.

A second technique was to use the present tense for the narratives. Narratives are told in the present tense to bring a sense of the child's life to stories which are always memory reconstructions of past events and feelings. As Harden and colleagues (2000) noted, even though the narratives that emerge in interviews are situated in social worlds outside the interview, the accounts that children tell are particular to that interview context and they may tell different stories to their friends, parents or another interviewer. The decision to use present tense has some implications, given that narratives were constructed from interviews conducted at different points in time. I have endeavoured to achieve clarity about the chronology of events by inserting linking phrases in brackets to locate the event in time.

A third technique was to present narratives in the first person to make clear that the story is that of the child. I juxtapose children's first person accounts against my voice as researcher, to make clear that there are two types of narrative running parallel: individual narratives presenting children's perspectives of their social worlds and my research journey to develop those narratives.

The family profiles and individual narratives provide extensive detail of the social context for each child. These are located in the appendices (Appendix H). Table 5 presents a summary of demographic information about the seven children.

Table 5 Demographic information

Name	Age*	Location	People living at home	Mother's marital status	Mother's employment status	Home tenure status
Damien	11 years	Rural town	Mother	Single mother	Part-time (supported employment)	Private rental (disability service); home ownership
Harrison	9 years	Large city: outer suburbs	Mother, father, brother	Married	Unemployed	Home ownership
Mia	8 years	Large city: suburbs	Mother, twin sister	Single mother	Unemployed	Public rental
Michael	10 years	Inner city; coastal town	Mother, older brother, twin brother	Single mother	Unemployed	Public rental; emergency accommodation
Olivia	8 years	Large city: outer suburbs	Mother, younger brother	Single mother	Unemployed	Private rental
Rosie	8 years	Large city: suburbs	Mother, twin sister	Single mother	Unemployed	Public rental
Simon	10 years	Inner city; coastal town	Mother, older brother, twin brother	Single mother	Unemployed	Public rental; emergency accommodation

- * Age reached at child's birthday during the study.

8.5.   Data analysis

A multi-stage analytic process was used to gain understanding of the interconnected influences across the social worlds of the children in recognition that children experience their lives as multiple, intersecting social worlds (see Figure 1; Figure 4, section 8.5.3). Analysis involved using the individual narratives to explore key features in the social worlds of home, school, peers and neighbourhood for each child (Stage One) and common themes that were apparent within the social worlds of the seven children (Stage Two). This identified influences in each child's four social worlds and different expression of themes within the social worlds of the group. The third stage of analysis used Stage One and Two findings to compare influences and themes across the seven children. This resulted in the detection of a pattern indicative of influences in the overall social worlds of the group. The next section details the methods used to conduct this multi-stage analysis, the stages of which are depicted in Figure 1.

Figure 1: The data analysis process
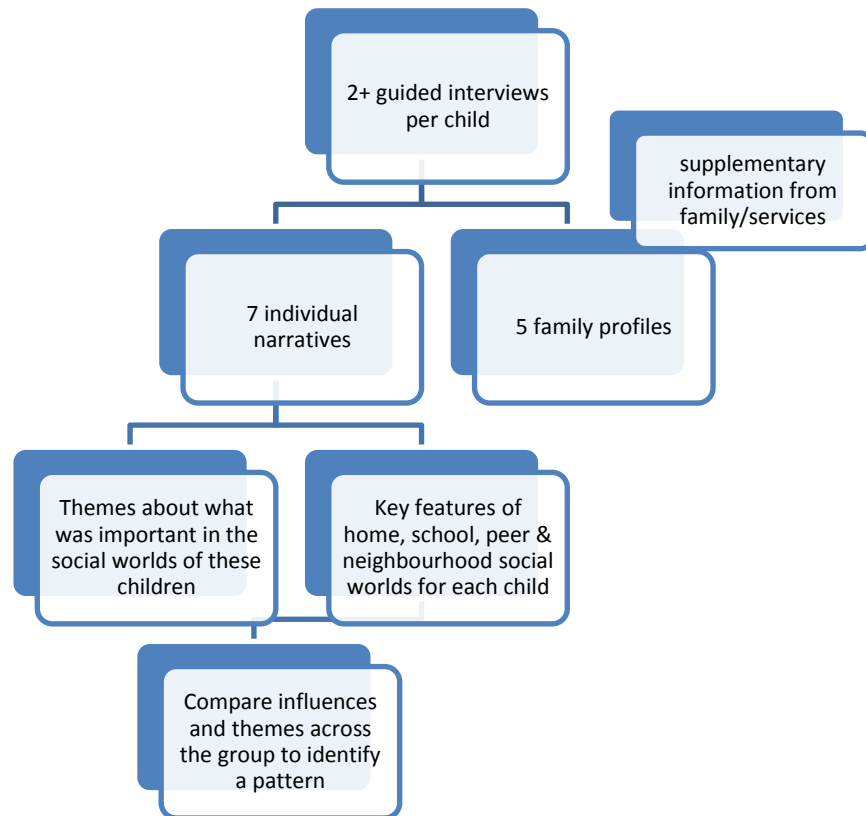
8.5.1. *Stage 1: Key features in the four social worlds of each child*

Individual narratives were used to understand influences in the home, school, peer and neighbourhood social worlds of these children. This section explains the analytic process undertaken to identify key features in the four social worlds of each child.

The framework I used to identify key features of home, school, peers and neighbourhood for these seven children was based on the five semi-structured interview guide topics (home, family, school, friends, and community) and my understanding about key features of these four social worlds gained from the literature about middle childhood as demonstrated in the earlier literature review chapters. The following key features were identified as important in the four social worlds of the children: home-based support networks and everyday routines and rules; duration of schooling and familiarity with this setting, views of teachers and schoolwork; perceptions about peer interactions and friendship; views of, and movements around,

the neighbourhood. By analysing these features in each child's social worlds it was possible to identify influences present in the four social worlds of individual children.

As literature presented in Chapter 5 (section 5.3.1) shows, home remains an important context for children in middle childhood and a key environment they share with their mothers. This makes the home of interest for my study about the influences for children of mothers with intellectual disability. Two main features that were important in the social world of home for children were: 1) support networks and 2) everyday routines and rules. The rationale for this focus and a description of the method used to conduct analysis are outlined below.

Support networks

Studies of middle childhood demonstrate that the support networks in which mothers are engaged influence their children's social experiences (Grimes et al*.,* 2004; Schneider et al., 2001). Chapter 2 outlined research about the support networks of mothers with intellectual disability indicating that some mothers lack adequate social support. To understand the support networks of the children I used a published typology of support networks for mothers with intellectual disability.

The support network typology, reviewed in Chapter 2 (section 3.2.1), was developed by Llewellyn and McConnell (2004) from a study of mothers and their family, friends, neighbours and service providers. It identified differences in support networks aligned with three particular household configurations: mothers living alone with their children; mothers living with a parent or parental figure; and mothers living with partners. Household configuration was associated

with support network features that were service-centred (mothers living alone with their children); local family centred (mothers living with a parent or parental figure); and dispersed family centred (mothers living with partners). The three household types differed in their support characteristics, with mothers living alone with children facing risk of social isolation.

In the current study the support network typology was used to explore the fit between the support networks of mothers with intellectual disability and their children, which extends the typology's original purpose. Close reading of each child's narrative identified household characteristics similar to those established in the typology of support networks for mothers with intellectual disability. An additional feature identified in this study was support received from another significant adult, as noted too in the bioecological approach (Bronfenbrenner, 2001) that underpins this study. Table 5 (see Chapter 9, section 9.2.1) compares the support networks of these children to the support network characteristics outlined by Llewellyn and McConnell (2004).

Everyday routines and rules

Routines are part of the structure of everyday life. Family-based rules contribute to everyday routines and therefore also warrant exploration. Guided by Bronfenbrenner (1979), I argue that exploring the everyday routines and rules of children assists in understanding influences in the social world of home. These aspects of family life were gauged to be topics about which children were likely to have views in middle childhood. With expanding social worlds comes increased awareness of differences in the routines and rules at, for example, home and school (Mayall, 1996). These topics were addressed in the interview

guide and the children were invited to reflect on their own home-based routines and rules as aspects of family life.

In this study I define routines as activities that children identified as part of their everyday lives. I define rules as standards of behaviour and activities that the children identified, including both permissible and forbidden activities and behaviour. Close reading of each individual narrative was used to extract information about everyday routines and rules at home as presented in Table 7 (see Chapter 9, section 9.2.1).

The three other social worlds that are central to this thesis—school, peers and neighbourhood—were analysed together. This was done in recognition of their interconnectedness and this grouping for analytic purposes does not suggest that they are less important social worlds for children in middle childhood than the home. However, this thesis about children of mothers with intellectual disability is driven by a research question about the influence of a potentially restricted social context for mothers on their children and , as such, separate analysis of their key shared social world (home) was warranted.

The social worlds of school, peers and neighbourhood were explored as separate topics in guided interviews from which the individual narratives were created. The interview guide introduced topics about school, peers and neighbourhood. Based on interview data that was used to construct individual narratives, coupled with a review of literature about middle childhood (see chapters 5 and 6), key features about these social worlds discerned in the children's individual narratives were identified.

School

Each of the seven children had been at school for between three and six years at the time of recruitment. As stated, attending school was one of their key everyday routines. Interview data on this topic focused on getting to/from school (analysed as a home-based routine), the length of time they attended their current school and their familiarity with it, views of schoolwork and teachers, in the classroom and playground.

Peers

Peers represent a distinct social world for analytic purposes but, unlike the other three social worlds explored in the thesis, peers are not restricted to any one physical setting but span multiple social worlds. To avoid repetition, any stories that were found to be about peer interactions that took place at school or in the neighbourhood were analysed solely under the topic "peers". The key aspects of the children's peer social worlds concerned how they viewed their peer interactions, including activities they engaged in with friends, the composition of friendship networks and bullying.

Neighbourhood

Important features of the neighbourhood social world were the structured activities children participated in and their unstructured movements around their neighbourhood. Children's access to friends in their neighbourhood was also important, again underlining the extent to which peers intersect with other social worlds in middle childhood.

Table 8 (see Chapter 9, section 9.2.2) describes the influences in the social worlds of school, peers and neighbourhood for each child that emerged through an analysis of the key features of these three social worlds.

8.5.2. *Stage 2: Themes within the four social worlds of the seven children*

This thesis is underpinned by the theoretical foundation of bioecological theory (Bronfenbrenner & Ceci, 1995; Bronfenbrenner & Morris, 1998) which addresses the interconnected nature of a child's social worlds. In recognition that children's social worlds are interconnected analysis of four individual social worlds for these children was followed by an investigation of common themes within their social worlds as a whole. Differences in the way themes manifested in the lives of individual children were identified.

NVivo software (version 10) was used to code data from the children's individual narratives. This involved extracting from the narratives linguistic units such as phrases, sentences and paragraphs that expressed a single point or referred to a particular topic. A "node" was created and a name assigned to identify the topic. Node is the term used in NVivo to denote areas of interest for research purposes such as themes, people and places.

The first nodes created corresponded to the four topics of home, school, peers and neighbourhood. Home was separated into two parent nodes of "home" and "family" to capture two distinct aspects: everyday routines (home) and significant people (family). Each of these primary or "parent" nodes contained "child" nodes. I created child nodes for positive and negative experiences with friends and family, and child nodes of relationships and environment for the settings of home, school and community. All

seven individual narratives were closely re-read to identify where they aligned with either parent or child nodes.

At this point I asked two questions of the coded data. These were: What did the linguistic units within that node have in common? What did a particular node identify about social worlds (one or overall) of the children? This led to ongoing revision of node configuration and naming. Figure 2 read from left to right shows the node creation and revision process.

Figure 2: Node generation and revision

home	relationships, environment	chores, pets, weekends, christmas			
family	positives, negatives	family life, siblings, mum, problems with family	supportive people, reliable people, keeping your word, mum	That mum is okay, feeling connected, being treated fairly	having control, things making sense, getting help, losing someone
school	relationships, environment	conflict, peers, self-view, anxiety	being acknowledged, being treated fairly, getting help		
peers	positives, negatives	best friends, play, conflict, birthday parties	supportive people, reliable people, keeping your word	feeling connected, being treated fairly, being accepted	
neighbourhood	relationships, environment	weekends, play, places	feeling safe, feeling threatened, feeling connected		

On one child's narrative, dual coding and comparison was undertaken with an experienced NVivo coder. There was substantial compatibility in the linguistic units both coders selected but I created substantially fewer nodes than the experienced coder because I had added to existing nodes instead of creating new ones in instances where they lacked sufficient congruence. On reflection, I realised that this created potential confusion about the purpose of that node. Following the dual coding exercise I modified my approach to embrace more expansive node generation and to be more descriptive of elements within settings rather than restricting coding to the setting itself. For example, the parent nodes called "home" and "family" were deleted and five new nodes were generated called "chores", "family life", "siblings", "problems with family" and "pets". This process was repeated with the remaining parent nodes. An example of how this occurred in the "family" node is presented in Figure 3. Figure 3 outlines the way that linguistic units initially classified under the node called "family" came to be spread across six of the final 11 nodes.

Figure 3: Generating themes about family
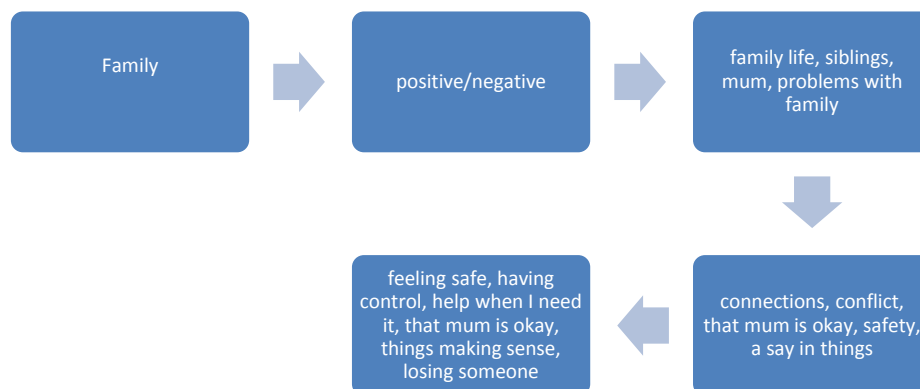
Through the process of reviewing individual narratives and existing nodes, previously unidentified people, places, events and feelings were identified and new nodes generated to accommodate these. As Figure 2 shows, the process resulted in nodes

being added to capture special events such as "birthday parties" and "Christmas", interpersonal difficulties such as "problems with family", "conflict" and "anxiety" and moral values such as "keeping your word". Over time, these nodes were merged with others or renamed to reflect growing appreciation of the meaning of the linguistic units within a node. When nodes contained fewer than three units I presumed that they had been misnamed or they duplicated another node. In these cases the node contents were emptied before deletion. For example, a node called "mum" became "that mum is okay" to reflect that the focus was about children protecting or worrying about their mothers. The units that comprised "keeping your word" and "being treated fairly" were found to be identical, so the former node was deleted and its contents moved to the latter.

Thematic analysis was completed when no new nodes could be identified and all remaining nodes contained linguistic units that shared a unifying focus or theme. At this stage I reviewed all eleven nodes and it became clear that they were linked to a parent node which I called "things that are important in my life". I reviewed these nodes and found they could be grouped into four main themes which were assigned names to capture the meaning of their constituent nodes (see Table 8, Chapter 9, section 9.3).

Thematic analysis identified four themes that represent key elements the children regarded as important in their lives. These were protection, agency, validation and trouble. Unsurprisingly, given that children encounter their social worlds as individuals, differences were noted in how these themes manifested in the social worlds of each child. For example, Simon experienced trouble as safety threats posed by exposure to volatile and violent adults. Michael shared the same home and neighbourhood as Simon but experienced trouble as difficulty making friends and maintaining a connection with a significant adult.

Stage One analyses identified influences present in four social worlds of each child and Stage Two analysis identified common themes within all four social worlds of the children. Although these were themes shared by all seven children, they were expressed somewhat differently for individual children, highlighting influences that shape particular social worlds and pointing to potential underlying, or primary, influences operating across their overarching social worlds.

8.5.3. *Stage 3: A pattern across the social worlds of the group*

Using the research outputs from Stages One and Two, I conducted a third and final stage of analysis to determine whether there was any pattern/s of influences present across the social worlds of this group of children. Stage Three involved re-examining findings about home, school, peers and neighbourhood to decipher whether any one of the four social worlds appeared to exert a demonstrable influence on the interactions children had in other social worlds. I re-examined the key influences in the four social worlds that had emerged (section 8.6.3) and the themes of protection, agency, validation and trouble within the children's social worlds (section 8.6.4).

A brief summary was compiled for each child that detailed the key features found in their four social worlds and the expression of the themes in their lives. Summary information was tabulated to permit comparison across the group. Table 10 (see Chapter 9, section 9.4) presents a comparison of the influences in the children's four social worlds. Individual children experienced protection, agency, validation and trouble differently. By examining findings about the way themes played out for each child alongside findings about key influences in their four social worlds it became possible to interpret what these differences meant for understanding influences across the overall social worlds of the group.

Stage Three analyses produced two outputs which are 1) details of influences and themes across the overall social worlds of the group and 2) a pattern in the influence of home on other social worlds. Figure 4 outlines the outputs for each stage of analysis.

Figure 4: Research outputs from multi-stage analysis

Stage 1
• Influences present in 4 social worlds of each child

Stage 2
• Common themes within all 4 social worlds of the children

Stage 3
• Influences and themes across the group
• A pattern in the influence of home on other social worlds
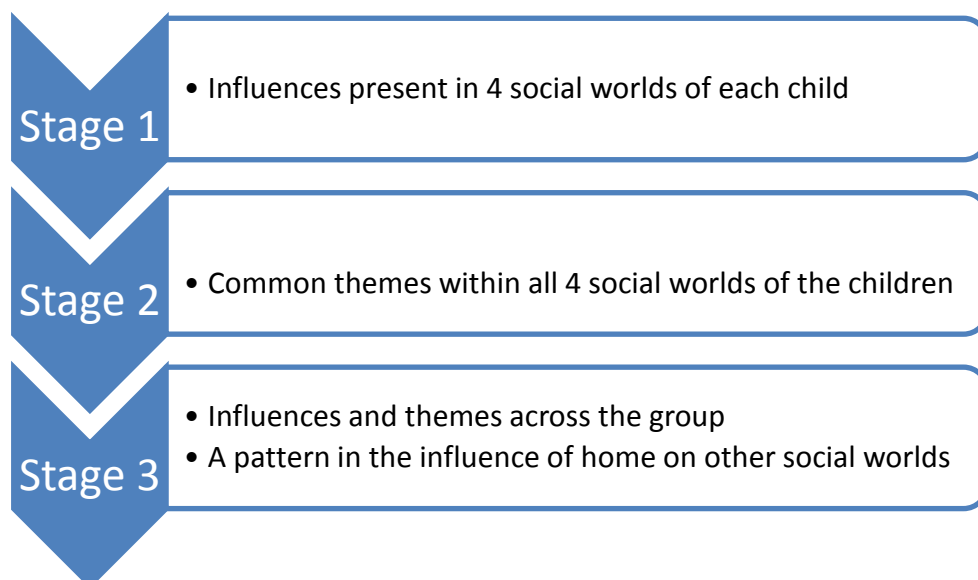
8.5.4.   *The social worlds of the twins*

Four of seven children in this study were identical twins. Stage One analysis examined the home, school, peer and neighbourhood social worlds for each twin, together with aspects of their social worlds shared with their co-twin, in their individual narratives and family profiles, respectively. Stage Two analysis reported specificity for each twin in the influences in their four social worlds and noted where being a twin shaped how themes played out in the social worlds of some twins. I re-examined the information about twins available from this analysis to investigate the possibility that having a same-aged peer who shares many of a child's social worlds was a specific influence in their overall social worlds. I reviewed their individual narratives and extracted references made to being a twin and cross-referenced this to findings about each twin's four social worlds and the way themes played out within their social worlds. This process revealed that, notwithstanding that it was an intrinsic part of these four children, no pattern related to the influence of being a twin on social worlds in middle childhood above and beyond that already identified in Stage Three emerged. This result is considered in terms of existing literature about the social worlds of twins in middle childhood in the next chapter.

8.6.   **Reporting the results**

The next chapter report findings from the study conducted using the methods outlined here. Chapter 9 is divided into three main sections. The first section reports the findings from analysis of individual narratives about key features in the social worlds of home, school, peers and neighbourhood of each child that highlight influences in these social worlds. The second section reports the results of thematic analysis conducted on the individual narratives to reveal common themes present within all four social worlds of the seven children. In the third section I present findings about a

pattern in the way that influences in one social world (the home) come to exert an influence on three other social worlds for the group. The possibility that twinness is a separate influence in four children's social worlds is explored based on re-examination of findings across their four social worlds. The chapter concludes with a list of the key findings.

CHAPTER 9:INFLUENCES IN THE SOCIAL WORLDS OF THE CHILDREN

9.1.   **Introduction**

Two questions drove the study: 1) what are the influences in the social worlds of

children of mothers with intellectual disability and 2) what is the influence of a

potentially restricted social context for their mothers on the social worlds of children?

This chapter addresses these questions by presenting the results from analysis of the

children's individual narratives (see Appendix H).

9.2.   **Findings: Influences in the four social worlds of each child**

Interview data from which the individual narratives were constructed included guided

interview topics that corresponded to these four social worlds. By examining

children's individual narratives it was possible to identify several key features that

children saw as important in each of these social worlds. An analysis of these features

of the social worlds of individual children enabled influences that operated in each of

their social worlds to be identified.

Findings about school, peers and neighbourhood are presented together in recognition

that children's social worlds overlap and that dis/continuities in their experiences

across social worlds can be more clearly identified when they are seen together. Home

is separated for analytic purposes to allow detailed examination of two key features of

this social world that children share with their mothers with intellectual disability and

is, as such, a key focus of investigation.

9.2.1.   *Influences in the social world of home for each child*

Home remains at the centre of children's social worlds, even as those worlds expand

in middle childhood. The influences that shape their lives at home radiate from here to

other social worlds through, for example, the impact of social support on parenting practices (Andresen & Telleen, 1992; Attree, 2005) and the influence of maternal social networks (Simpkin & Parke, 2001; Uhlendorff, 2000) and maternal attachment (Blair et al., 2013; Schneider et al., 2001) on children's peer interactions. In line with the centrality of home for middle childhood and the importance of this social world in terms of the research question about the influence a mothers' social context has on her children's social worlds, findings about home are presented first. Analyses of two key features of home, 1) support networks and 2) everyday routines and rules, are presented. Table 6 describes the support networks in the children's homes using the concept developed in the support network typology of Llewellyn and McConnell (2004), as described in Chapter 2 (Section 2.3.1). The typology serves as a framework from which to examine the children's support networks with its delineation of three distinct networks for these mothers, being local family centred, dispersed family centred and service centred networks.

Table 6: The support networks of the children

Child	Support network	Significant adults	Type	Aligned with Typology	Different to Typology
Damien	Single mother Limited extended family	Never met father No visits from extended family	Service-centred	Small network size Infrequent contact with family	
	Mothers' boyfriend	Infrequent visits from mothers' boyfriend		Few friends, neighbours	
	Extensive formal services	Daily contact with carers: focused on child and mother		High proportion of formal support	Long-term support, stable social relationships
Harrison	Two parents Extended family	Parental focus on child Regular visits from extended family	Dispersed family-centred	Relatively large support network, high proportion of family	Family ties are local
	Friends and neighbours	Regular contact with mothers' friends			High proportion of friends and neighbours
	Limited formal services	Focused on mother, not child		Low proportion of formal support	
Michael	Single mother No extended family	No current contact with father No visits from extended family	Service-centred	Small network size. Infrequent contact with family	
	Church community	Attend community events, no visitors			
	Formal services	Regular weekends with mentor (at home 1): focused on child Episodic formal services, focused on mother		High proportion of formal support, short-term, less stable relationships	
Mia	Single mother Godmother, extended family	Never met father Frequent contact with godmother, focused on child and mother	Service-centred		Large network size
	Family friends and neighbours	Regular contact with friends and neighbours			Frequent contact with family, local family

	No formal services				Low proportion of formal services
Olivia	Single mother Limited extended family	No contact with father Contact but no visits from extended family	Service-centred	Small network size	
	No friends or neighbours	No visitors to home		Infrequent contact with family	
	Limited formal services	Focused on mother, not child		High proportion of formal support; short-term, less stable relationships	
Rosie	Single mother Godmother Extended family	Never met father Frequent contact with godmother, focused on child and mother Visits from extended family	Service-centred		Large network size
	Family friends and neighbours	Regular contact with friends and neighbours			Frequent contact with family, dispersed family
	No formal services				Low proportion of formal services
Simon	Single mother No extended family	No current contact with father No visits from extended family	Service-centred	Small network size Infrequent contact with family	
	Church community	Attend events but no visitors			
	Limited formal services	Focused on mother, not child		High proportion of formal support; short-term, less stable relationships	

Support networks

Support networks are seen here as the people who, in the eyes of the children, played a regular and supportive role in their lives. The composition of support networks for these seven children based on their individual narratives was analysed by asking: 1) who lived with a child or visited regularly, and 2) who were the significant adults the child saw frequently (family, friend, neighbour or formal service) and what was the nature of the relationship? These aspects of support networks are depicted in the far left-hand columns of Table 6 under the headings *Support network* and *Significant adults*.

Typically, the children had support networks that comprised more formal than informal support. Regular support from extended family was uncommon and fathers were notably absent from the support networks of the children. Harrison was the only child who lived with his father and he also had regular contact with extended family. The support networks of children with single mothers were most socially restricted when they lacked the ongoing involvement of another reliable adult whose support for a child was connected to their home. Mia and Rosie's support network is an example of a network that involved family, friends and neighbours and in this network they had access to reliable and regular support from their godmother. Michael's support network was socially restricted but he had regular, ongoing contact with a mentor from a formal service until he moved out of the area, which demonstrates that reliable support from another adult is dependent on a connection between the adult and that child's home.

The two columns on the far right-hand side of Table 6 depict the degree of alignment with or divergence from the support network typology of mothers with intellectual disability. Homes that matched the typology were characterised as having service centred support networks. An example of a home that conformed to the service centred network was that of Michael and Simon who lived with a single mother and had little or no contact with extended family, neighbours or friends. Formal services were episodic. Each of the three homes with support networks that differed substantially from those described by the social network typology is outlined:

Harrison's home initially appeared to be a dispersed family centred network in that he lived with two parents and had contact with both extended families, but he also had regular access to the large support network of his mother, which did not conform to this type.

Damien's support network differed from a typical service centred network because the formal services were long-term and focused on his specific needs, not just those of his mother.

Rosie and Mia lived with a single mother but their support network was not typical of a service centred type. It included a supportive godmother and was devoid of formal services. The network had many features typically found in a local family centred network except that the adult who supported their mother, their godmother, did not share their home.

Everyday routines and rules

The second aspect of the children's home life that was analysed was the presence (or lack) of routines and rules. Bioecological theory argues that the rules and routines of home life present children with opportunities to develop new skills and beliefs about themselves (Bronfenbrenner & Ceci, 71994) and are important to understanding how they interact with others. Table 7 describes the everyday routines and rules drawn from an analysis of interview data that was used to construct their individual narratives.

Table 7: Everyday routines and rules at home

Child	Everyday routines	Rules
Damien	Twice-daily visits from paid carers Carers drive to/from school, help with homework Attends structured after-school program Played soccer for several years Plays computer games and friends visit at weekends	Help with cooking Clean the dishes Make own bed Take clothes to laundry
Harrison	School pick up/drop off by mother Father works during week Attends holiday program Has played soccer for several years Father helps with homework, makes rules	No TV before school Not allowed to make breakfast Take garbage out Don't fight with brother Look after brother No playing football
Michael Home #1	Walk self to school Attend after-school youth centre, Regular weekends with mentor "auntie"	Take clothes to laundry
Michael Home #2	Walk self to/from nearby school	If he goes to bed early the man living there won't drink.
Michael Home #3	School further away, walks to/from with mother	None stated

Mia	Mother walks to/from school Discuss tuckshop lunch order with godmother Calls/visits and weekends at godmother's Shopping with neighbours, tutor for homework Weekly sport club	Make own bed Clean and tidy bedroom Make own breakfast but no cooking Share and get along with sister. Water plants and clean dishes at godmothers'
Olivia	Mother drives to/from school, Mother helps with homework Commenced after-school activities (swimming, dancing, craft, cooking)	Keep own bedroom tidy Set the dinner table Look after younger brother In charge of TV
Rosie	Mother walks to/from school Discuss lunch order with godmother Calls/visits and weekends at godmothers' Shopping with neighbours, tutor for homework Weekly sport club	Keep own bedroom tidy Make own breakfast but no cooking Have healthy lunch No fighting with sister
Simon Home #1	Bus to/from special school, walk to other school Attend youth centre after school	Not allowed to make breakfast
Simon Home #2	Walk self to/from nearby school	
Simon Home #3	School further away, walk to/from with mother Swim in motel pool	

All the children spoke about everyday routines around getting to and from school and after-school activities, and it was unusual for them not to mention multiple and comparable everyday routines that could be distinguished by type of routine and familiarity with the timing and features of that routine. Damien was an example of a child who had clarity about everyday routines such as the names of the carers who came to his home on a given day and which activities they assisted him with. In their first home, the twin brothers described fewer everyday routines than other children, except for getting to and from school and daily visits to a youth centre. As housing circumstances became more precarious over two home changes, their everyday routine became limited to the task of getting themselves to and from school.

Typically, the children were aware of rules governing the chores for which they were responsible, such as tidying their room, but their understanding of what was expected in terms of interactions, such as how they treated siblings, depended on features of a particular home. Homes with rules governing how children treated each other and structured chores provided children with a level of security and clarity. Harrison lived in a home where he was expected to de-escalate conflict with his younger brother even when he was not responsible for initiating it, possibly because his brother had a learning disability, but he understood and accepted the rule. An example of a home without clear rules was that of the twins Simon and Michael. Simon could not identify any household chores and Michael said that he sometimes took dirty clothes to the laundry. Typically, the twins interacted with each other in displays of frustration and aggression and there was conflict between their older brother and mother.

In summary, some homes are social worlds which offer children reliable routines and rules and access to another significant adult apart from their mother and others lack such predictability and support.

9.2.2. *Influences in school, peers and neighbourhood social worlds*

Three other social worlds that were a focus of interest in this study were school, peers and neighbourhood. Each has been the focus of substantial research for their likely influence on children in middle childhood, as presented earlier in this thesis. Examination of the key features of these three social worlds for the seven children was used to identify individual and group-based influences. Key features of these intersecting social worlds are analysed together to identify influences for each child. Table 8 describes the children's school, peer and neighbourhood social worlds.

Table 8: The social worlds of school, peers and neighbourhood

Child	School	Peers	Neighbourhood
Damien	Always been at same school Likes school, good at maths. Likes some teachers	Best friend and stable friendship network, regular contact outside school Some older boys bully younger kids	Friends visit him and he them; goes to shops with mum, carers, friends Fishing, ball games, walks dogs with carers
Harrison	Always been at same school, feels close to teacher Mum is involved in fundraising activities of the school P & C	More comfortable with "special needs" peers. Finds a best friend to play teddy games with	Prefers home to neighbourhood Nana is "crossing lady" at school Befriends a local peer Sees mother's friends
Mia	Always been at same school Sat beside friend until teacher moved her Mum was a classroom helper in the past	Best friend changes with new school year Has stable friendship network	Sees mothers' friends, elderly neighbours and extended family Attends sports club
Michael (before move)	Always been at same school Likes teachers Good at maths	No best friend or stable friendship network Wants a boy to befriend him	Rides bike, goes to youth centre, plays on streets Knows neighbours
Michael (after move)	Likes new school	Makes two new best friends	none stated
Olivia	Always been at same school (bar 3 months) Likes schoolwork and teachers. Good at maths, in choir Wants mum to get involved in craft classes	Large friendship network Changes best friends and friendship network over the year.	Mother won't let her talk to neighbours Makes a friend when mum doing door-to-door sales Starts local social groups
Rosie	Always been at same school & getting better at reading, Likes teachers, asked to look after new girl	Best friend changes with new school year but stable friendship network.	Sees mothers' friends, elderly neighbours and extended family Attends sports club
Simon (before move)	At local primary since kindergarten At special school for 3 years, hates school	No stable friends but plays with some boys	Rides bike, goes to youth centre, plays on streets, Knows neighbours
Simon (after move)	Attends local school, hates school	Hasn't made friends	None stated

9.2.3. *School*

All the children went to school and this was a setting in which they spent a large proportion of their time but they had different feelings about their experiences there. For the group, school was seen primarily as a setting for interactions with peers, but whether these were viewed positively or not depended on the kinds of peer interactions they expected to have at school. For the children who saw school positively it was because it gave them a chance to develop friendships and to engage in play and, when their homes lacked support from extended family or friends, school was a social world in which they could build supportive friendship networks. Olivia viewed school in this way: the social opportunity it offered was important because she did not see her friends away from school. Children who were less positive about school saw it as a place where they would be bullied or ostracised by peers. This was the case for Simon who held negative views of all three schools he attended during the study and faced persistent peer rejection and bullying.

As a group, the children saw teachers mainly as authority figures who exercised control over students, but their perceptions differed as to whether teachers used their authority for their benefit. Damien did not necessarily like all the teachers at his school but he did see them as guardians of the students in their care. Children who were most critical of teachers were those who believed that teachers failed to use their authority status for the good of students. Michael liked school despite feeling bullied and ostracised by peers but he did not trust that teachers would protect him from bullies and suspected them of turning a blind eye to bullying.

9.2.4. *Peers*

Peers were an important social world for children that intersected with their other social worlds, particularly the school and neighbourhood. Children wanted to get along with peers and to make (and keep) friends but some found this easier than others. When they were confident that peer interactions would be positive they were in a better position to overcome difficulties and persist in seeking opportunities to make friends than if they expected to be rebuffed or to have unrewarding peer interactions. Children formed their views about the type of peer interactions they could expect from past experiences. Olivia, for example, saw herself as having a stable friendship network and as being well-liked, and her optimism about peer interactions helped her overcome a public rejection by a friend. Children who felt rejected by peers and had no friends were left in doubt about their ability to form friendships, but could gain confidence if their experiences changed. Michael felt he had no friends and was being bullied at the school he had attended since kindergarten; with a change of school he was able to make new friends and became more optimistic about peer interactions.

9.2.5. *Neighbourhood*

The children engaged more or less actively and independently in the neighbourhood, influenced by their age and whether they or their mother felt their neighbourhood posed a threat to their safety. Damien, for example, had relative autonomy in his movements around the neighbourhood as he approached adolescence, with regular visits to the homes of his friends, and he felt his small rural town was a safe place to live. Safety concerns may not have reduced the freedom of older children as much as that of younger children. Simon and Michael were also older children who moved freely around their neighbourhood. In their case, however, this was despite being conscious of safety risks, such as public substance use, swearing, and the threat of

189

burglary. In contrast, when the mothers of younger children viewed the neighbourhood as unsafe their children could perceive that they were restricted in their ability to spend time in playgrounds and meet friends. Mia and Rosie stopped playing outdoors after their mother was threatened by a stranger, and their contact with friends away from school was under her supervision.

In summary, analysis of the key features in the four social worlds of the individual children identified what it was about these features that influenced their social worlds. These influences are:

1. Predictability (or lack) of everyday routines and rules at home

2. Presence (or lack) of a significant adult at home

3. Stability (or lack) at school based on familiarity, trust in teachers, confidence with schoolwork

4. Friendship stability (or lack), confidence (or lack) in peer interactions

5. Neighbourhood safety and freedom of movement.

These results begin to distinguish differences between these influences in the social worlds of individual children. Stage Two continues this investigation by analysing recurrent themes within the children's social worlds to understand how these influences shape the overall social worlds of these seven children.

9.3.   Findings: Themes within the four social worlds of the children

In this section, recurrent themes within the social worlds of the seven children are analysed. NVivo software was used to code data from the children's individual narratives. Linguistic units were extracted from each child's narrative and "nodes" generated to represent a single point or topic. A process of continuous revision was undertaken until no new nodes could be identified and all remaining nodes (eleven)

were found to represent a shared core element. These could then be grouped according to aspects of life the children regarded as important. Four groups were distinguished and assigned a name, or theme, to denote their constituent nodes. The four themes identified were protection, agency, validation and trouble. While themes found different expression depending on the particularities of a child's social worlds, the identification of these four themes highlights commonalities across the four social worlds of the group. Each theme is comprised of more than one component which relates to a unique dimension of the theme. Table 9 describes the grouping of the final nodes into themes.

Table 9: Recurrent themes about what children viewed as important in their lives

Final list of nodes	Grouped nodes	Themes
1. Help when I need it 2. That mum is okay 3. Being treated fairly 4. Feeling threatened 5. Losing someone 6. Feeling connected 7. Being accepted 8. Being acknowledged 9. Having control 10. Things making sense 11. Feeling safe	Feeling safe Help when I need it That mum is okay	Protection
	Having control over my life Things making sense Being treated fairly	Agency
	Being accepted for who I am Feeling connected Having my talents recognised	Validation
	Losing someone Feeling threatened	Trouble

The main theme is summarised and then the way its components were manifest across particular children's social worlds are discussed.

9.3.1. *Protection*

Protection was something children sought from others, particularly adults in their lives. Depending on an individual child, a sense of protection was implied rather than necessarily called upon. Children also experienced themselves as protectors; this was in the specific context of protectiveness toward their mothers. The three elements of protection are discussed.

Feeling safe

In stories that ranged from the everyday to more dramatic examples, the children demonstrated that feeling safe was a priority. Everyday examples of feeling safe include Harrison seeking comfort from his mother following nightmares. Significant adults played a role in children's sense of safety. This was underlined, for example, by the stories Mia and Rosie told about their godmother, whose presence created a feeling of safety. That was vividly demonstrated in Mia's story about a time their godmother had jumped fully clothed into a swimming pool to rescue a drowning Rosie.

Help when I need it.

Despite differences in the way it was manifested for each child, all seven children expressed a desire for help to be timely and responsive. Six children had someone to help them apart from their mothers. Whether they perceived help to be timely and who they relied on for help differed depending on the access their support networks provided to adults other than mothers. Damien and his mother

had a support network without family, friends or neighbours, but he regarded the carers as people who offered him help. Olivia was the only child who saw friends as a source of help and this might be because she lacked another adult in her support network.

That mum is okay.

Six children expressed a sense of protectiveness toward their mothers, ranging from concerns about her physical safety and wellbeing to defending her from criticism or harm. Knowing their mothers were okay made the children feel safe and protected. Rosie's story about threats to her mother's life from a stranger demonstrates that she saw her own safety and that of her mother as interlinked. There were distinct differences in the types of harm children were concerned about their mothers facing, from physical violence to hurt feelings, and some children felt their mothers were at risk living in their unsafe neighbourhood. In Damien's case, protectiveness was not for his mother's safety but rather for her social acceptance, expressed in him choosing friends whom he could trust to accept that "mum needs help". Whether children were protective did not depend on whether their mothers had other adults in their lives. Harrison was protective of his mother, comforting her when she was criticised by others, in spite of his father being an available source of support.

9.3.2. *Agency*

Agency was expressed in a desire for some autonomy and control over decisions that affected them. The children recognised the limitations to their agency in aspects of their lives, such as where they lived, while still wanting to have their opinions about

these matters heard. Children's agency appeared to find different expression depending on whether it was in response to interactions with adults or peers.

Having control over my life.

Having control over their life was a desire the children shared. It was expressed in different ways, depending how much control children sought, which aspects of their life they wanted to be able to control, and whether they saw adults as restricting their agency. Harrison really wanted to control the way people acted towards him so that he could avoid his own "angry and stressed" reactions. The children who felt they had limited control over their lives responded differently depending on their circumstances. Olivia sought agency by demanding some control over when and where she saw friends, because she perceived this was denied her; Simon exercised agency through declarations about who he would live with and where, because he lacked housing stability and safety. In both cases, it was beyond the child's control to determine whether the desired outcome was achieved, but stating their wishes manifested their agency.

Things making sense

A second dimension of agency was making sense of things that happened and using this information to achieve goals. An example of making sense of things comes from Damien, who reached his own conclusions about why there were no photos of his father at home by deciding that his mother must have buried them when he died. Olivia used an understanding about her mother's reluctance to let her visit the homes of strangers by creating opportunities for her mother to get to

know the parents of her friends. This was designed to achieve her aim of seeing them away from school.

Being treated fairly

All the children felt that being treated fairly by others was a sign of respect. Adults were perceived to be fair when they did not show favouritism and granted children a say in their lives, but whether this was the case depended on how positively children viewed the adults in their life. Simon was pessimistic about the likelihood of fair treatment by adults in general and teachers in particular whereas Olivia, who felt her mother unfairly restricted her access to friends, was optimistic that she could convince her mother to change this situation. Whether children expected unfair treatment from other children and their response to it differed depending on their confidence in peer interactions and what was at stake in defending their right to fair treatment. Olivia minimised the rejection of her party invitation to maintain friendship status quo which she valued highly, whereas Harrison was unwilling to forgive a friend who punched him, deciding to end the friendship despite having few others.

9.3.3. *Validation*

Feeling that they were accepted by people they valued was important to all of the children. This theme had three distinct components.

Being accepted as an individual

Implicit in being an individual was being seen as unique. This could involve a risk of ostracism for being different but could equally mean not being mistaken for someone else. Harrison was a child who refused to deny his own game

choices and conform to the choices of other children in order to gain peer acceptance. For four children, the desire to be seen as an individual was potentially compromised by being a twin, but only one experienced it as a possible barrier to her individuality. Mia preferred not to have identical belongings or share toys with her sister and was conscious of the ever-present risk of being mistaken for her twin. She disapproved of her best friend tricking people about which twin she was. That this friend went on to become her twin sister's best friend may be emblematic of Mia's perception that she was expected to share things with Rosie.

Feeling connected

All the children had at least one person who made them feel positive about themselves and, in most cases, this was their mother. Everyday expressions of feeling connected included Damien's mother watching him play computer games "because she likes to watch" and Rosie's summing up the connection between herself, her twin sister and her mother as "when we're sad we hug her and when she's sad we hug her".

Having my talents recognised

All the children saw themselves as good at something, but whether their skills were supported and fostered by those around them depended on their ability to gain public recognition. Children who undertook specific training to develop their skills, such as Rosie and Mia with their athletic abilities, were able to achieve recognition but other children's talents either went unnoticed or they lacked opportunities to develop them. Simon saw himself as talented at computer

games but he played alone at the youth centre; Harrison saw himself as a good dancer but had limited ability to demonstrate this because he was too shy to perform in public.

9.3.4. *Trouble*

Troubling events and their impact on the children varied, underlining the substantial differences between their overall social worlds. For some children, trouble was largely limited to minor relationship difficulties such as feuds with friends or family members. Other children experienced more traumatic loss, uncertainty and safety threats.

Losing someone

Some children had experienced the loss of important people, including parents, grandparents and friends, through various life events including moving house, ending friendships and death. The impact of these losses on children depended on how positively the child viewed that relationship rather than whether the lost person was a close relative or not. Olivia replaced her friendship network with the change of school year but, despite her focus on friends, did not experience this as a loss because she felt she still had ample close friends. Damien's stories about the death of his father and unborn sisters suggested he saw these losses as part of his life history rather than as emotionally charged events, whereas the move interstate of his best friend was a painful event. Michael felt the loss of his volunteer mentor acutely because, despite only having monthly contact with her, she had been the most significant other adult in his life apart from his mother for several years.

Feeling threatened

Trouble also took the form of threats to the safety of some children or their loved ones, showing that events did not necessarily have to be experienced personally by a child to be seen as threatening. Rosie felt fearful about a physical attack on her mother and Olivia was cautious around strangers, after both their mothers were physically or verbally threatened. Two children who faced the most immediate threats to their safety were Simon and Michael, who saw adults as unpredictable, especially when there were "lots of people drinking" or "people that take drugs". Their optimism about the future when they moved to the motel may be indicative of the relative security they felt now that they were living with only their mother.

In summary, an analysis of these four themes demonstrates the extent to which they played out in sometimes divergent ways within each child's overall social world. For example, trouble was expressed quite differently for a child who had experienced the loss of a loved one or serious threats to safety compared to one for whom trouble was encountered largely in more everyday examples, such as arguments with friends. Differences between the expressions of trouble in the lives of co-twins underline the point that influences are shaped by the interaction between an individual child and their social worlds. For example, Rosie but not Mia expressed concern for their mother's safety in their neighbourhood following a threatening encounter. Given that themes even found different expression in the social worlds of twins demonstrates that understanding common influences for the group must be balanced against attending to the particularity of the individual. Nonetheless, the themes do represent

commonalities across these children's four social worlds and may signal shared influences for them as a particular group of children. For example, in the generalised concern this group of children expressed for their mothers' safety and wellbeing and the need to feel they had access to help when needed. A pattern across the overall social worlds of all seven children is now reported.

9.4. Findings: A pattern of influences

This section details a pattern in the influences that shape the social worlds of the group. The finding is based on the results obtained from a multi-stage analytic process which included distinguishing how themes played out in the lives of individual children and differences between the key features in each child's home, school, peers and neighbourhood social worlds. In Stage Three, these findings were analysed by comparing what was known about each of the seven children and then determining if their interactions across their four social worlds formed a discernible pattern indicative of a common influence (or influences). Table 10 presents a comparison of influences across the social worlds of the group of children.

Table 10: Comparing influences across the four social worlds of the children

Child	Home	School	Peers	Neighbourhoods
Damien	Stable, predictable routines Another significant adult (formal services)	Stable, familiar (same school, positive view of teachers, confident about schoolwork	Stable friendship network, new best friend after a house move	Safe, quiet town
Harrison	Stable, predictable routines Another significant adult (father)	Stable, familiar (same school, positive view of teachers, confidence about schoolwork	Few friends, some ostracism made a friend	Limited contact with neighbours but has local support network
Mia	Stable, predictable routines Another significant adult (godmother)	Stable, familiar (same school, positive view of teachers, confident about schoolwork	Stable friendship network, new best friend after arguments	Some friends but restricted movement, safety concerns
Michael	No stable, predictable routines No other significant adult	Less stable, familiar (changed school, negative view of teachers) but confident about schoolwork	Friendless, bullied, made a friend with a move	Safety concerns, negative view of some adults, freedom of movement in neighbourhood
Olivia	Stable, predictable routines No other significant adult	Stable, familiar (same school, positive view of teachers, confident about schoolwork	Close friendship network and best friend in but changes over new school year.	No contact with neighbours and negative view of some, safety concerns, restricted movement
Rosie	Stable, predictable routines Another significant adult (godmother)	Stable, familiar (same school, positive view of teachers, confident about schoolwork	Stable friendships, a new best friend in new school year	Safety concerns, negative view of some neighbours, restricted movement
Simon	No stable, predictable routines No other significant adult	Less stable, familiar (changed school, negative view of teachers, not confident about schoolwork.	Friendless, bullied	Safety concerns, negative view of anti-social adults, freedom of movement

The only pattern discernable was the influence of the home social world on the other social worlds–school, peers and neighbourhood. Across the seven children there were three distinctly different home social worlds on two dimensions. These were (a) reliable (or fewer, or non-existing) routines and rules and (b) a significant adult in addition to a mother with intellectual disability. The pattern of influences was dependent on stability, predictability and the presence of another significant adult, but it played out in three different ways. First, a home social world that provided stability and predictability and the presence of another significant adult, other than their mother with intellectual disability. Three homes, those of Damien, Rosie, Mia and Harrison were like this. Second, represented only by all three homes in which Michael and Simon lived during the study, was a home social word that provided no routines and rules and lacked the presence of another significant adult in the children's lives. Third, represented by Olivia's home, was a home social world that provided stability and routine but lacked support from another adult apart from the mother.

Living in these three home social worlds exerted a different influence on the way that children approached their three other social worlds. The pattern played out in the following way:

Three of the four children who came from homes with predictable routines and at least one supportive adult other than their mother confidently experienced the other three social worlds beyond their homes. They were Damien, Rosie and Mia. All three had secure friendships and positive views of school. Harrison was less confident about social interactions with peers but had positive and secure relationships with significant adults. Having Asperger's syndrome was likely to explain his peer difficulties, and in

spite of some experiences of bullying and ostracism, Harrison demonstrated optimism about future peer interactions and found a friend who accepted him.

Both children from homes that lacked stability and predictability and support from another significant adult were pessimistic about their interactions in the three other social worlds. Michael and Simon both experienced their home as lacking predictability, had less positive views of school and experienced peer rejection and bullying. Simon's interactions with adults and children alike were characterised by conflict and he was pessimistic about the likelihood of positive social interactions at home and beyond. Although the three homes in which the boys lived lacked the involvement of another supportive adult, Michael had enjoyed an ongoing supportive relationship with a volunteer mentor before moving house. The temporary presence of this figure in his life might explain his greater optimism about future peer interactions than his brother. Michael's peer interactions improved after moving house when he made two friends at school.

Olivia's home social world was similar to Michael and Simon's in the sense that it lacked the ongoing, reliable support of another adult apart from her mother. However, the effect of this absence on social interactions for Olivia differed to that of the twin boys. The lack of a significant adult did not impair her confidence that she would enjoy positive interactions, as it had for Michael and Simon. She was highly confident in her social interactions and had secure friendships and a positive view of school. It is possible that her apparent determination to acquire friends and increase her social participation was a reaction to her socially restricted home. Over time, her social participation improved noticeably and this was at least in part a result of Olivia's own intervention in the form of her sustained campaign to persuade her mother that she

should be allowed to join after-school activities. In the case of Olivia, the impact of lacking a significant adult on her approach toward social interactions appeared to be offset by her superior social skills.

Before moving on to report the main findings I examine what, if any, separate influence above and beyond the pattern described being a twin represented in the four social worlds of the two identical twin pairs[9].

9.4.1. *Twinness as an influence for four children*

Findings about the four identical twins reported in Stages One and Two were re-examined to determine whether this aspect of their lives represented an additional influence on their overall social worlds. Both pairs of twins spent a substantial amount of their time in many shared social worlds but whether an individual twin viewed this as an advantage in their social interactions or not depended on their overall social worlds. The two homes of these twins differed according to the two dimensions outlined in the previous section. Mia and Rosie lived in a home with predictable routines and rules and support from a godmother whereas Michael and Simon's home(s) lacked stable, reliable routines and rules or support from another adult. As findings reported throughout this chapter have shown, the twin boys faced difficulties in social interactions that were found to relate to a pattern in the influence of their home on other social worlds.

In terms of their home social worlds, both sets of twins lived with a single mother. The twin girls spent most of their time with their mother (and godmother) in the

---

[9] Existing research about the social worlds of twins in middle childhood is considered in Chapter 10 (see section 10.6).

company of the other twin. The extent to which this was a shared social world is indicated by Mia's story about a special time spent with her mother and away from Rosie being a hospital stay some years earlier. In contrast, Michael and Simon shared their (first) home with their mother and older brother but actively avoided spending time together. Shared social worlds for twins potentially led to something of a dual, rather than singular, perspective on their social interactions. For example, Mia and Rosie used the first person plural pronoun to refer to things that had happened to one of them in addition to activities they had undertaken together. The girl twins both told of a time when one of them had burnt herself cooking pancakes. According to Rosie the injury was hers whereas Mia recalled that "we burnt ourselves". That Mia could recall the event as if it had happened to her suggests a unique connection existed between these twins; no such connection was evident for the twin boys.

Having a same-age companion might have offered the twins a source of stability and security when their social world restricted their access to support. This was the case for Michael and Simon, who experienced rapidly changing social worlds over the course of the study. After moving to their third home the twin boys began to engage in joint activities such as playing in the motel pool and walking to school together with their mother. Mia and Rosie had many common friends across their social worlds but maintained separate friendships in the school classroom and playground. That one twin girl's best friend became her twin's best friend over the course of the study suggests that there was the potential for competition over friends. This was also indicated by Mia's concern that being a twin might prevent people from seeing her as an individual and her dislike of attention attracted by her and Rosie's physical similarity. Similarly, Simon felt "bad" when he was mistaken for his twin. Although Michael and Simon did not share friends, as the twin girls did, neither twin boy had

any close friends and both felt themselves to be bullied and ostracised by peers. The divergence in the way the two sets of twins approached their peer social worlds suggests that confidence in peer interactions had less to do with the specific influence of being a twin than with the influence of their home as a foundation for interactions in their other social worlds. In summary, while being a twin was intrinsic to these four children, and the twin girls were uniquely attuned to each other, there was no specific pattern to the way being a twin influenced their overall social worlds above and beyond that identified for the group as a whole.

The next section identifies the key findings in the study. The contribution these findings make to existing literature about children of mothers with intellectual disability and middle childhood is discussed in the next chapter.

9.5. **Main findings**

The main findings about the social worlds of the children in this study are:

The social world of home for the children of mothers with intellectual disability in middle childhood is not necessarily restricted, even when the social context of their mother is restricted.

Predictable routines and rules and support from another significant adult in the homes of mothers with intellectual disability can create a stable home base from which their children may confidently approach interactions in other social worlds.

Formal services can function as a significant adult for children of mothers with intellectual disability by providing child-focused services for children whose mothers' homes have small support networks.

Children of mothers with intellectual disability whose homes lack another significant adult may be motivated to counteract this social restriction by utilising social opportunities available in their other social worlds.

Children of mothers with intellectual disability can build supportive friendship networks that compensate for social restrictions in their support networks at home

Children of mothers with intellectual disability from homes without stable routines and rules or another significant adult may be pessimistic about having positive interactions in their other social worlds

 Children of mothers with intellectual disability with communication or behaviour disorders may have low expectations of rewarding interactions in their social worlds

Children are protective of their mother with intellectual disability when they fear a threat to her safety or wellbeing in the neighbourhood

CHAPTER 10:   DISCUSSION

10.1.   Introduction

The study was conducted to address a research gap in knowledge about influences in the home, school, peer and neighbourhood social worlds of children of mothers with intellectual disability, including the influence of the potentially restricted social context of their mothers on the children's social worlds. Until now there has been very little attention paid to these children in the context of the four main social worlds in middle childhood, with the exception of Faureholm's (2010) prospective and Booth and Booth's (1998) retrospective studies and empirical research about the social world of school (Feldman & Walton Allen, 1997; O'Neill, 1985; Perkins et al., 2002). This chapter discusses the findings of the current study in terms of each of the four social worlds to determine what they add to the literature reviewed in Chapter 3 about children of mothers with intellectual disability and, more broadly, within the literature about the four social worlds of other children in middle childhood, reviewed in Chapters 5 and 6.

Children's social worlds intersect such that several findings from the study apply to more than one social world. The social world in which each finding is reported is that which offers the most compelling contribution to existing knowledge.

10.2.   The social world of home

Finding: The social world of home for children of mothers with intellectual disability in middle childhood is not necessarily restricted, even when the social context of their mother is restricted.

A key finding in the current study is that social restrictions for mothers with intellectual disability that impact on their support networks and, therefore, at home for their children, do not inevitably lead to restrictions at school, with peers or in the neighbourhood. The findings from this study add to existing knowledge about the support networks of mothers with intellectual disability by viewing home from the perspective of children. Until now, knowledge about support networks was based solely on studies conducted with mothers (Feldman et al., 2002; Llewellyn & McConnell, 2002, 2004; Stenfert-Kroese et al., 2002; Traustadóttir & Sigurjónsdóttir; Tucker & Johnson, 1989).

In the current study, two of the five mothers with intellectual disability had large support networks that included another significant adult (husband or godmother), extended family, friends and neighbours, from which it would be expected that the children would approach school, peers and the neighbourhood with more confidence than the children from the three homes that lacked extensive support networks. However, this was not necessarily the case. Two of the three children with extensive support networks at home approached social interactions with confidence and the third, a child from a two-parent family, was less confident about peers, possibly due to his communication disorder. Four of the five mothers were single mothers who lived alone with their children, which, it has been suggested, leads to reliance on professional support and a risk of social isolation (Llewellyn & McConnell, 2002, 2004; Llewellyn et al., 1998). However, this was not necessarily the case. Two of the four single mothers were not socially isolated. These were a mother who did not rely on formal services and a mother who received ongoing professional support. Their children were positive about their support networks, possibly because their mothers were not socially isolated. In two homes mothers were socially isolated, yet their

children were not necessarily socially isolated in their social worlds of school, peers and neighbourhood. A child living in one such home was confident in social interactions in her other three social worlds, whereas twin brothers in the other home approached social interactions with pessimism. These findings where the mothers' support networks and their children's interactions in their social worlds (including their home) do not align suggest that social restrictions for children do not inevitably flow from a socially restricted context for mothers.

Finding: Predictable routines and rules and support from another significant adult in the homes of mothers with intellectual disability can create a stable home base from which their children may confidently approach interactions in other social worlds.

The study confirms earlier findings about influence of the social world of home on learning opportunities for the children in middle childhood (Aunos et al., 2008; Feldman & Walton Allen, 1997). In this study two influential features in the children's homes were identified which shaped children's interactions in other social worlds beyond the home. These two features are, first, having predictable routines and rules and, second, having another significant adult at home.

Children from homes with clear, reliable routines and rules that they perceived to be fair and consistent were able to use this foundation of stability to approach social interactions in their other social worlds with confidence. These children were optimistic about having positive social interactions, which made them capable of negotiating difficulties in their social worlds, including those related to peers, such as arguments with friends, changes to friendship networks and encounters with bullies.

A significant adult in the children's homes was most likely to be an individual, such as a father, extended family member or family friend. Paid carers from formal services could also perform the role. Studies of mothers with intellectual disability have documented the importance of another significant adult, usually the mother's mother, who respects the primary role of the mother with intellectual disability in her child's life and offers timely and appropriate support that enhances their parenting capacity (Llewellyn & McConnell, 2004; Stenfert-Kroese *et* al., 2002; Traustadóttir & Sigurjónsdóttir, 2008; Tucker & Johnson, 1998). This person, whom Traustadóttir and Sigurjónsdóttir (2008) called "the mother behind the mother" was also present in the retrospective accounts of childhood documented by Booth and Booth (1998) and Traustadóttir and Sigurjónsdóttir (2005). The person who was the other significant adult, connected to a child's home social world but not necessarily living with the child and mother, helped create a foundation of stability at home that promoted confidence in children to approach their other social worlds with optimism about positive interactions.

The findings about the role played by a significant adult in the lives of children is consistent with the proposition from bioecological theory that another significant adult who shares a long-term commitment to the child's wellbeing is important, both as a parenting support for mothers and through interactions between the adult and a child, as a motivator for the child to engage in activities that stimulate learning (Bronfenbrenner, 2001). The findings in the current study show that a significant adult who is engaged in the home of a mother with intellectual disability can facilitate her child's engagement in activities and interactions that promote new skills and confidence, such as by joining sports teams and social groups and finding special interests. The role was particularly influential in the school, peer and neighbourhood

social worlds of children who, by virtue of their mother's restricted social context, might otherwise have lacked these opportunities.

Finding: Formal services can function as a significant adult for children of mothers with intellectual disability by providing child-focused services for children whose mothers' homes have small support networks.

Previous research about formal services has examined the role of formal services as social support to mothers with intellectual disability but not in relation to their children (Feldman et al., 2002; Llewellyn et al., 1998; Llewellyn & McConnell, 2002, 2004; Stenfert-Kroese et al., 2002). Cleaver and Nicholson (2007) suggested that the episodic and short-term nature of services has been blamed for less than optimal child outcomes for these children.

In contrast, the findings from this study demonstrate that formal services can be a potentially important source of support for the children of mothers with intellectual disability and can play a positive role in their social worlds. This is possible when formal services are tailored to an individual child's needs and not exclusively focused on their mother. Formal services were engaged, to varying degrees, in four of the five homes of children in the study, but only in one case did a child have access to ongoing, reliable and tailored support from a formal service. The formal service supported that child to develop interests and talents and to spend time with friends away from home, demonstrating that to meet a child's individual needs, formal services may need to look beyond the home a child shares with the mother with intellectual disability to the child's other social worlds. That child approached his other three social worlds with confidence and enjoyed stable friendships despite his mother having a support network devoid of extended family, friends and neighbours.

Several studies of social support for mothers with intellectual disability have noted that single mothers who rely on the support of formal services in the absence of family or friends often view service providers positively, and even as their friends (Ehlers-Flint, 2002; Llewellyn & McConnell, 2002, 2004, Llewellyn et al., 1998). Formal service workers can represent an enduring relationship for children whose support networks are otherwise restricted, and this may be similar to the friendship role formal services were found to play for their socially isolated mothers.

10.3.   **The social world of school**

Finding: Children of mothers with intellectual disability whose homes lack another significant adult may be motivated to counteract this social restriction by utilising social opportunities available in their other social worlds.

Previous qualitative research has suggested that these children may face peer difficulties such as bullying and ostracism (Booth & Booth, 1998; Faureholm, 2010; Ronai, 1997). Empirical studies of psychological or academic outcomes in middle childhood have reported stigma related to mothers' intellectual disability (Perkins et al., 2002), and behavioural (Aunos et al., 2008; O'Neill, 1985) and academic (Feldman & Walton Allen, 1997) problems at school when mothers were socially isolated and stressed.

In the current study, the children viewed the social world of school primarily as an opportunity to make and sustain friendships and learn how to interact with peers. Two of the four children who were confident that they would have rewarding interactions at school lived with mothers who lacked support from extended family, friends and neighbours and saw school as a social world in which they could create supportive friendship networks.

This perspective of the children differed from that of adults. One study – an autobiographical account (Ronai, 1997) – suggested that inspiring teachers could mitigate the damage of a socially restricted and abusive home social world on a child's attitude to learning. Studies from the developmental literature have indicated that a positive teacher-child relationship can improve the peer interactions of rejected children by improving their social skills and reducing aggressive behaviour (Berry & O'Connor, 2010; Troop-Gordon & Kopp, 2011).

10.4.   **The social world of peers**

Finding: Children of mothers with intellectual disability can build supportive friendship networks that compensate for restricted support networks at home.

To date, knowledge about peer interactions for these children is very limited, with findings confined to reports of negative experiences at school and isolation in neighbourhoods from a very small number of studies which employed diverse research designs (Booth & Booth, 1998; Faureholm, 2010; Perkins et al., 2002; Ronai, 1997). Substantial developmental literature has been devoted to understanding the influence of peers on children's adjustment (for reviews see Berndt, 2004; Rubin et al., 2006a) but results diverge about the relative influence on children of peer acceptance and dyadic friendships, with some studies finding that peer rejection is more damaging than friendlessness (Klima & Repetti, 2006) and others that peer acceptance does not prevent loneliness for friendless children (Parker & Asher, 1993). In the current study, peer interactions and friendship experiences differed across the group. Four of the seven children had overall positive views of their friendships and peer interactions, two children had some difficulty making friends and getting along with peers, and one child experienced persistent friendlessness and bullying.

Researchers have found that friends can be a particular source of support for children experiencing family adversity (Criss et al., 2002) and that high-quality friendships are associated with positive adjustment to peer victimisation (Malcolm et al., 2006; Schmidt & Bagwell, 2007) and increases in life satisfaction for children in general (Nickerson & Nagle, 2004) and, more specifically, for children from disadvantaged neighbourhoods (Rogers, 2013). The children in the current study were all from disadvantaged backgrounds. Four children had mothers with intellectual disability whose social context was restricted by limited (or non-existent) support from extended family, friends or neighbours. The study found that children used the increasing opportunities available across their school, peer and neighbourhood social worlds to build supportive friendship networks. These peer networks may provide an important compensation for the absence of extended family (or similar) support at home. Two of the four children from homes without support from extended family enjoyed high-quality, supportive friendships, and each had a best friend over the duration of the study. This suggests that friends have a potentially important role in the social worlds of children from homes that offer limited social opportunities.

Finding: Children of mothers with intellectual disability from homes without stable routines and rules and another significant adult may be pessimistic about having positive interactions in their other social worlds.

This study adds to existing knowledge within the developmental literature about the influence of the home on children's peer interactions in middle childhood. Earlier research has reported that mothers influence the size (Uhlendorff, 2000) and quality (Blair et al., 2013; Simpkin & Parke, 2001) of their children's friendship networks. The current study adds to this knowledge by focusing on interactions across the four

social worlds of home, school, peers and neighbourhood. The finding that two features in the social world of home –namely, predictable routines and rules and another significant adult – influence the way children approach interactions in other social worlds where they spend time with peers contributes to knowledge about the influence of the home on peer interactions. Four of the five children who came from homes that offered a stable foundation of social interactions elsewhere enjoyed mainly positive and rewarding peer interactions. One child, who had a diagnosed communication disorder, experienced greater difficulties interacting, but a stable home social world provided the support he needed to be optimistic about his prospects for making friends.

Finding: Children of mothers with intellectual disability with communication or behaviour disorders may have low expectations of rewarding interactions in their social worlds.

To date, knowledge about the children of mothers with intellectual disability who themselves have a disorder or disability that impacts on communication or behaviour is in its infancy. In two qualitative studies which included retrospective (Booth & Booth, 1998) and prospective accounts (Faureholm, 2010), there were children who themselves had intellectual disability. Faureholm (2010) suggested that these children experience more peer rejection and stigma, whereas Booth and Booth (1998) found the opposite, with their adult children with disabilities reporting less peer rejection and stigma.

In the current study the three children (all boys) who had difficulties with peer interactions had poor social skills, likely related to the presence of a diagnosed behaviour or communication disorder. Two of these children approached their social

216

worlds away from home with pessimism about rewarding interactions, but one of them made a friend after changing school; this may be in line with an earlier finding about the mutability of peer status for children who are socially withdrawn but not actively disliked by peers (Oh et al., 2004). A third child who had a communication disorder was more optimistic about peer interactions.

10.5. **The social world of the neighbourhood**

Finding: Children are protective of their mother with intellectual disability when they fear a threat to her safety or wellbeing in the neighbourhood.

Until this study only that of Booth and Booth (1998) had addressed children's experiences of their neighbourhoods. In studies in the developmental literature, together with those informed by the sociology of childhood, researchers have examined the growing importance of the neighbourhood in middle childhood.

The current study includes a group of children who were from socioeconomically disadvantaged backgrounds. An association has been established between intellectual disability and low socioeconomic status (Emerson, 2007), including for parents with intellectual disability (IASSID SIRG, 2008) as reported in Chapters 2 and 3. The children lived in a variety of neighbourhoods, including densely populated urban centres and suburban (inner and outer) areas and rural and coastal towns. Six were living in a large city at the time of recruitment and their neighbourhoods were in socioeconomically disadvantaged areas.

Studies of children's perceptions of their disadvantaged and dangerous neighbourhoods have found that they view these neighbourhoods as posing health and safety risks, and denying them opportunities for play and access to friends (Carvalho et al., 2012; Mier et al.; 2013; Rogers, 2013). In the current study, four of the seven

children felt that their neighbourhood posed a potential threat to their own or their mother's safety or wellbeing from anti-social behaviour, criminal adults, or verbal hostility. Only one child, who lived in a small rural town, considered his neighbourhood a safe place for children.

In this study there was no evidence that dangerous neighbourhoods could expose children to developing or exhibiting deviant behaviour in middle childhood (as found by Ingoldsby & Shaw, 2002). The two children who had freedom to move around a neighbourhood that they felt was dangerous did not engage in deviant behaviour. Similarly, an earlier finding about the risk of loneliness for children whose mothers restricted their movements around dangerous neighbourhoods (O'Neill et al., 2011) was not supported in this study. Both the children whose freedom to move around the neighbourhood was restricted by perceived dangers enjoyed rewarding peer interactions; one of them was from a socially restricted home. In contrast, the two children who moved freely around a neighbourhood which they regarded as posing safety threats were lonely and rejected by neighbourhood peers.

Earlier researchers have reported that the children of mothers with intellectual disability typically hold positive views of their mothers (Booth & Booth, 1998; Faureholm, 2010; Traustadóttir & Sigurjónsdóttir, 2005), although some studies included accounts of ambivalence toward mothers in adolescence (Booth & Booth, 1998; Faureholm, 2010) or adulthood (O'Neill, 2011; Ronai, 1997). The finding in this study that five of the seven children felt protective toward their mothers comes from outside the children's homes. The concerns held by four of the five children were directly related to fears for their mother's physical safety or emotional wellbeing posed by threats from adults in their neighbourhood.

In the previous chapter I concluded that being a twin did not exert an influence, above and beyond the influence of their home social world, on the other social worlds of the four twins in the study. However, this study did not explicitly set out to examine the influence of twinness on the social worlds of children in middle childhood. The next section considers how my conclusion aligns with a small body of research that has specifically examined this topic.

10.6.   Contribution to literature about the social worlds of twins in middle childhood

In a review of research about the social experiences of twins in middle childhood, Thorpe and Danby (2006) argued that, in contrast to earlier studies focused on the risks associated with reduced maternal involvement for twins, such as higher rates of attention deficit hyperactivity disorder (Levy et al., 1996) and language delay (Hay & O'Brien, 1987, cited in Thorpe & Danby, 2006), there was growing evidence to suggest that being a twin can present a social advantage. Being a twin may present a unique source of social learning through early opportunities to negotiate and share with same-aged peers (Pulkkinen, Vaalamo, Hietala, Kaaprio & Rose, 2003). Moreover, identical twins have been found to share more than half of their total friendship pool and to be significantly more likely than non-identical twins to share friends in middle childhood (Thorpe & Gardner, 2006). This creates a potential for conflict and competition which may be greatest for identical twin girls and may be a strategy to assert their individual identity (Danby & Thorpe, 2006).

The identical twin girls in this study had several friends in common, which aligns with the earlier finding of Thorpe and Gardner (2006). Notably, the best friend of one twin became her twin sister's best friend during the time of the study and this twin worried that people might fail to see her as an individual and resented an expectation that she

219

share with her twin. However, the conflict and competition previously found to exist for identical twin girls in middle childhood (Danby & Thorpe, 2006) was not typical of the interaction between these twin girls. The confidence of the twin girls in their social interactions, found to be influenced by their stable home base, may have also have been influenced by the opportunities that being a twin presented for learning to negotiate with a same-aged peer (Pulkkinen et al., 2003). However, the situation was different for the twin boys. They experienced peer difficulties and lacked a foundation of stability in their social world of home, which suggests that the home exerts a greater influence than twinness on twins in middle childhood.

CHAPTER 11: CONCLUSION

This thesis concludes with consideration of the study's contribution to research, education and policy about children of mothers with intellectual disability. Limitations of the study and their potential implications for the results are discussed and recommendations for future research based on these results are proposed. I begin with some reflective comments on the research journey and how my thinking about childhood and the children of mothers with intellectual disability has evolved.

11.1. Reflections

I embarked on this study with the aim of understanding how having a mother with intellectual disability affected the life of a child. My presumption that maternal intellectual disability would have an impact on the lives of children came from reading the literature skewed toward investigation of problems with the parenting provided by mothers with intellectual disability and from professional engagement with caseworkers working with mothers with intellectual disability who faced multiple forms of disadvantage. Over time, as I came to question my initial assumptions, I found myself hearing different stories. I read accounts of childhood from adults and, more rarely, children, some of whom talked about stigma and ostracism in their community but also of the very "normal" bonds of maternal love and connection that existed. The focus in these studies was largely on the homes children and their mothers shared. I had met mothers with intellectual disability in the context of the formal services they received and found that the focus here, too, was on the home. In searching for a way to hear the views of children in these families I became interested in learning not only about their home life but about the social worlds they encountered beyond the home. My effort to see them in terms of the totality of their social worlds

led me to embrace three theoretical frameworks that enlarged the way I thought about childhood and children.

This study weaves together the three theoretical positions of bioecological theory, the sociology of childhood and narrative theory. Each theory contributes individually to the study. It is to bioecological theory that the study owes its understanding that children actively shape their social worlds through interaction with others in their everyday lives. Children's lives, it follows, only make sense in the context in which they are lived. This insight steered the study toward a course of discovery about commonality and specificity in the social worlds of this group of children and what light their social experiences might shed on the lives of children with mothers with intellectual disability more broadly.

The sociology of childhood brings recognition that children, as social agents, have a unique perspective on their lives that can and should be heard in research about them. This recognition guided the choice of data collection methods that would foster their meaningful participation. Prior research has been preoccupied with early childhood development and our understanding of social experiences has been gleaned through a child development lens or informed by adult recollections of childhood. This study extends knowledge by hearing children's perspectives of their social worlds in middle childhood.

Bruner's approach to narrative adds to the study with the explanation that we tell stories to make sense of life and, by interpreting our experiences through these stories, we come to construct a perspective on our lives. Narrative interpretation helped me to understand the accounts children gave in interviews about their everyday lives and to

illuminate the particular influences that shaped their views of their social worlds, thus facilitating the identification of patterns in the influences across the group.

11.2. **Scope and limitations**

The investigation reported in this thesis focused on the social worlds of children who lived with their mother with intellectual disability because it was the influence of this social context that I set out to explore. Previous research has shown that mothers with intellectual disability may face social restrictions, but no investigation of their likely influence on the social worlds of their children had been undertaken. I addressed this research gap by conducting this exploratory study with children of mothers with intellectual disability. As a group, the children of mothers with intellectual disability are at elevated risk of being removed from parental care by statutory child protection authorities (Booth et al., 2005; Llewellyn et al., 2003; Taylor et al., 1991). Without question, this outcome would profoundly influence a child's social world. Thus, hearing about the experiences of these children undoubtedly warrants research attention. Such exploration, however, was beyond the scope of this study.

The findings primarily reflect the social worlds of children living with single mothers and must be interpreted cautiously in light of this sample parameter. In the small sample group, only one child came from a two-parent family or had an ongoing relationship with his father. However, the sample is consistent with other studies in the field in terms of relative socioeconomic disadvantage, single-parent status and formal service usage. Findings are drawn largely from families who use formal services, which could be described as a clinical population. All but one of the five families whose children participated were headed by mothers who were long-term current or past users of formal services to address parenting and disability-related

needs. The predominance of clinical populations in research involving parents with intellectual disability is well documented, as was noted in the literature reviews presented in Chapters 2 and 3.

A potential limitation implicit in a study of this nature is that the differences in age and generation between the children and me as a researcher could have influenced our interactions in ways that made some children less candid in expressing their views. To overcome this as much as possible, and guided by Mayall's (2000) suggestion for child researchers, I approached the children as an adult who was less expert than they about the research topic of childhood social worlds. I presented a welcoming and affable demeanour, wore casual dress and used informal language. I can only speculate that these endeavours were successful as all seven children accepted an invitation to participate in a second (and, in some cases, third) interview. While I found no direct evidence that generational difference acted as an impediment for children, I did note that both twin boys requested that their first interviews be suspended relatively quickly. They did not volunteer a reason and were, of course, not asked for one, yet when I invited them to meet me again both accepted. In an effort to ensure that discomfort with me and/or the interview process was not a barrier to their expressing their views, I sought to ensure that they were more comfortable in subsequent (two) interviews. I offered to interview them together, asked them to suggest a setting that might be more conducive than their front courtyard (the setting of the first interviews) and invited them to take regular breaks. This response was successful, with both boys appearing more comfortable and not asking to end the interviews.

## 11.3.	**Contribution to research**

At the start of the thesis I pointed out that literature about children of mothers with intellectual disability had been dominated by a focus on examining the risks that maternal intellectual disability might pose to a child's development and wellbeing. The overwhelming majority of studies in this small body of literature had been concerned with understanding developmental outcomes or issues related to abuse and neglect. Few studies had explored the lives of children and just one had presented the perspectives of children (while children) themselves. This bias in the literature might in itself contribute to a pervasively negative view of the risks posed to children of having a mother with intellectual disability by implying that there is *a priori* cause for concern about their developmental outcomes and wellbeing. The negative views of court representatives about the parenting provided by mothers with intellectual disability have been found to contribute to decision-making in child protection matters (McConnell, Llewellyn & Ferronato, 2006; Ward & Tarleton, 2007). The unique contribution this study makes to the literature is to challenge an underlying assumption that being raised by these mothers necessarily presents a risk to children.

Among the small group of studies to explore the lives of children of mothers with intellectual disability, there are accounts of social difficulties including stigma, ostracism and bullying, problems at school including truancy and early school leaving, and ambivalence toward their mothers (Booth & Booth, 1998; Faureholm, 2010; O'Neill, 2011; Ronai, 1997). Many of these studies also include accounts in which children talk of the unconditional love offered by their mothers and of the supportive mother-child relationships that survive into adulthood, including in the face of separation in childhood (Booth & Booth, 1998; Faureholm, 2010; O'Neill, 2011; Ronai, 1997; Traustadóttir & Sigurjónsdóttir, 2005). The findings of this study

contribute to our understanding of the lives of these children by exploring the particularity of their social worlds. As well, or in addition, taking a "wide lens" approach facilitates understanding of common influences in the social worlds of this group of children and influences that are particular to their individual home, school, peer and neighbourhood social worlds. Negative experiences, such as ostracism and bullying, although not common for these children, were a feature of the social worlds of some. By comparing their social worlds as a group, it was possible to understand which influences may have contributed to these difficulties.

To my knowledge, this is the first English-language study to present children's perspectives of their social worlds with a mother with intellectual disability at a particular life stage. Together with an earlier longitudinal study of childhood by Faureholm (2010), it represents the current state of knowledge about childhood from the perspective of children of mothers with intellectual disability. Hearing from these children makes clear that their lives in middle childhood are shaped by specific influences which present different challenges and opportunities, depending on the context for each child and their environment. Taking a children's perspective meant refusing to accept the "at risk" lens through which these children had typically been viewed in research. This study shows that whereas not all children have mothers with intellectual disability who face social restrictions, even those whose do can approach social worlds expanding beyond the home with confidence and optimism given an environment that supports their needs.

11.4. Contribution to education

These research findings make a contribution to future education of professionals who work with parents with intellectual disability. The results offer professionals a glimpse

of the particularity present in the social worlds of the children and the intersection between their homes and the social worlds of school, peers and neighbourhood. The study guides educators and those they teach to direct their attention toward the intersections between the social world of home and other social worlds for potential learning opportunities for children. It shows that creativity and flexibility are required in the approach taken to supporting children in these families and, above all, the findings direct professionals to approach children with a view to understanding the particularity of their social worlds. It is through this that understanding about their lives can be gained and appropriate support offered.

11.5. **Contribution to policy**

A significant implication that can be drawn from these findings for policy about formal services to support families headed by mothers with intellectual disability concerns a potential role for formal services in the lives of the children. Four of the five families received formal services, most of which took the form of short-term, episodic services directed toward the needs of a mother with intellectual disability. Services ranged from crisis housing to independent living skills to advocacy and casework. Only one of these families received services that actively focused on the distinct support needs of both the child and his mother. In this case, ongoing, regular and tailored support addressed the child's needs which included, for example, getting to sports groups and school, help with homework, and support to pursue an interest in fishing and soccer. For the three other families receiving formal services, these were directed solely to addressing the mother's needs, although in two cases children were engaged with a separate formal service. One child was part of a social group that provided respite for siblings of children with disability and another was involved in a program that matched mentors to disadvantaged children to enhance their social

opportunities. In these examples, support was either infrequent or temporary and, in the latter case, was shown to be unsustainable in the absence of a family-centred approach to the support needs of that child and his mother.

The findings suggest potential new directions for the formal services engaged to respond to the needs of mothers with intellectual disability and their children. For those responsible for allocating resources in these services, it is now clear that the social support needs of children in middle childhood are distinct from those of their mothers and cannot necessarily be addressed within the home or through services that respond solely to mother's needs. Support directed to mothers can equip them to build a stable home foundation from which their children approach other social interactions with confidence. However, services may fall short if they do not also direct attention toward the specificity of that child and the child's other social worlds. Children actively shape the social world of home through interactions with their mothers (and others) and these interactions are also shaped by interactions that take place in their other social worlds. In addressing the needs of children by, for example, actively helping them to spend time with friends and gain new skills, or by addressing barriers to rewarding social interactions, such as behaviour or communication difficulties, formal services can enhance children's receptivity to learning opportunities at home.

The findings suggest that a formal service can act as a significant adult for children of single mothers with intellectual disability raising children without support from extended family or friends. Children in these homes can lack access to support from another significant adult and formal services engaged with these families are well positioned to respond to this unmet need. However, this can only be achieved where

the social needs of the children are regarded as a priority and resources are deployed to respond to their individual circumstances.

11.6.   **Recommendations for future research**

This study marks a step forward in understanding about the lives of children of mothers with intellectual disability, yet many questions remain. I suggest the following areas as some that warrant future research attention in light of this study. This is not intended as an exhaustive list but as a way to build upon our knowledge in this field.

First, it is an unfortunate reality that, at least at the present time, statutory child removal is not an unlikely outcome for many children of mothers with intellectual disability. To date, the little known about the lives of children who are separated from their mothers with intellectual disability has been gained from some accounts of childhood reported in retrospective qualitative studies with adults (Booth & Booth, 1998; O'Neill, 2011; Traustadóttir & Sigurjónsdóttir, 2005). Studies designed to explore the issues around separation from their mothers would increase knowledge about an aspect of childhood pertinent to this particular group. In light of their elevated risk of statutory removal, hearing about childhood from the perspective of these children would give voice to a currently silent group. Studies to compare longer-term outcomes for children who remain with their mother with intellectual disability and those who are temporarily or permanently separated from their mothers would provide findings that might be used to guide policy and attitudinal changes for child protection.

The study highlights the relationship between the predictability of routines and rules in the home and social interactions elsewhere for children in middle childhood. This

finding offers many potential directions for future research. In-depth research to examine the everyday routines and rules of children would permit understanding of the specific influence of particular routines and rules that influence children's optimism about engaging in the social worlds beyond the home.

The study identified four themes in the aspects of life that the children considered important. Of these, a theme of protection may be particular to them as children of mothers with intellectual disability. Research to explore children's perspectives of their mother's vulnerability might build on knowledge about their developing awareness of her intellectual disability and the influence this exerts on their social worlds.

Coincidentally, the current study included three children with a communication or behaviour disorder that was found likely to have influenced their peer interactions. All three had some experiences of bullying and difficulties making friends; one of them experienced persistent peer rejection. These experiences made them less confident about their prospects of rewarding peer interactions in the future. As peers represent an increasingly important social world for children, difficulties with peers in middle childhood may leave children ill-equipped for changes to their peer social worlds in adolescence. Earlier studies of children of mothers with intellectual disability have noted difficulties with peers (Booth & Booth, 1998), including for children with intellectual disability themselves (Booth & Booth, 1998; Faureholm, 2010), but to date no study has explicitly addressed the influence of behaviour difficulties on the peer interactions of children of mothers with intellectual disability. Studies comparing the social worlds of children of mothers with intellectual disability who are accepted or rejected by peers might uncover particular influences across their social worlds that

shape peer interactions. Empirical studies of the particular needs of children of mothers with intellectual disability with communication or behaviour disorders may highlight effective behaviour strategies that can prevent peer difficulties becoming entrenched.

This study extends existing knowledge about support networks for mothers with intellectual disability by exploring support networks from the perspective of the children. Future research to explore support networks from the perspectives of both child and mother may highlight important differences in the way they view their support needs and contribute to an understanding of how best to respond to the distinctive needs of children and their mothers with intellectual disability.

The perspective of fathers – with or without intellectual disability – in the lives of these children has received little research attention to date, with the exception of a recent study by Wade et al. (2011) who found that fathers offered a unique source of social support for mothers with intellectual disability. A study that replicates the approach used in this study but extends the research parameters to hear the views of parents, as well as children, about the social worlds of children could build understanding of the role of the father as a significant adult in the social world of children of mothers with intellectual disability.

This thesis marks a small but valuable step in a larger research journey to understand childhood as it is experienced by a group of children who, while small in population terms, are over-represented in child protection matters and recognised usually (but not here) in stereotypes that paint their lives in a negative light.

REFERENCES

Amato, P., & Ochiltree, G. (1987). Interviewing children and their families: A note on data quality. *Journal of Marriage and the Family*, *49*(3), 669-675. doi: 10.2307/352212

Andresen, P., & Telleen, S. (1992). The relationship between social support and maternal behaviours and attitudes: A meta-analytic review. *American Journal of Community Psychology, 20* (6). doi:10.1007/BF01312606

Ahn, J. (2010). 'I'm not scared of anything': Emotion as social power in children's worlds. *Childhood. 17*, 94-112. doi: 10.1177/0907568209351553

Asher, S., & Coie, J. (Eds.). (1990). *Peer rejection in childhood.* Cambridge, NJ: Cambridge University Press.

Attree, P. (2005). Parenting support in the context of poverty: A meta-synthesis of the qualitative evidence. *Health and Social Care in the Community. 13*(4), 330-337. doi: 10.1111/j.1365-2524.2005.00562.x

Aunos, M., Feldman, M., & Goupil, G. (2008). Mothering with intellectual disability: Relationship between social support, health and well-being, parenting and child behaviour outcomes. *Journal of Applied Research in Intellectual Disabilities*, *21*, 320–330. doi:10.1111/j.1468-3148.2008.00447

Australian Bureau of Statistics. (2012). *Regional population growth Australia 2010-2011*. Canberra: Commonwealth of Australia.

Australian Bureau of Statistics. (2011). *Census of population and housing: Socio-economic indexes for areas (SEIFA) (cat. no. 2033.0.55.001).* Canberra: Commonwealth of Australia.

Bacon, K. (2006). 'It's good to be different': Parent and child negotiations of twin identity. *Twin Research and Human Genetics, 9*(1), 141-147. doi: 10.1375/twin.9.1.141

Bagwell, C. (2004). Friendships, peer networks, and antisocial behaviour. In J. Kupersmidt & K. Dodge (Eds.). *Children's peer relations: From development to intervention.* Washington DC: American Psychological Association. doi: 10.1037/10653-003

Bagwell, C., & Coie, J. (2004). The best friendships of aggressive boys: Relationship quality, conflict management, and rule-breaking behaviour. *Journal of Experimental Child Psychology 88*, 5–24. doi: 10.1016/j.jecp.2003.11.004

Balen, R., Blyth, E., Calabretto, H., & Manby, M. (2006). Involving children in health and social research: 'Human becomings' or 'active beings'? *Childhood*, *13*, 29-48. doi:10.1177/0907568206059962

Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, NJ: Prentice Hall.

Bayley, N. (1969). *Bayley scales of infant development: Birth to two years.* New York: Psychological Corporation.

Berndt, T. (2004). Children's friendships: Shifts over a half-century in perspectives on their development and their effects. *Merrill–Palmer Quarterly*, *50*, 206–223. doi: 10.1353/mpq.2004.0014

Berndt, T., & Ladd, G. (Eds.) (1989). *Peer relationships in child development.* New York: John Wiley and Sons.

Berry, D., & O'Connor, E. (2010). Behavioural risk, teacher–child relationships, and social skill development across middle childhood: A child-by-environment analysis of change. *Journal of Applied Developmental Psychology, 31*, 1–14. doi: 10.1016/j.appdev.2009.05.001

Blair, B., Perry, N., O'Brien, M., Calkins, S., Keane, S., & Shanahan, L. (2013, June 24). The indirect effects of maternal emotion socialization on friendship quality in middle childhood. *Developmental Psychology*. Advance online publication doi: 10.1037/a0033532

Booth, T., & Booth, W. (1994). *Parenting under pressure: Mothers and fathers with learning difficulties.* Buckingham, UK: Open University Press.

Booth, T., & Booth, W. (1998). *Growing up with parents who have learning difficulties*. London, UK: Routledge. doi: 10.1080/0968759032000080986

Booth, T., & Booth, W. (2000). Against the odds: Growing up with parents who have learning difficulties. *Mental Retardation*, *38*, 1–14. doi:10.1352/0047-6765(2000)038<0001:ATOGUW>2.0.CO;2

Booth, T., & Booth, W. (2003). In the frame: Photovoice and mothers with learning difficulties. *Disability & Society, 18*(4), 431-442. doi.org/10.1080/0968759032000080986

Booth, T., & Booth W. (2003). Self-advocacy and supported learning for mothers with learning difficulties. *Journal of Learning Disabilities*, *7*(2), 165-193.

234

Booth, T., Booth, W., & McConnell, D. (2005). The prevalence and outcomes of care proceedings involving parents with intellectual disabilities in the family courts. *Journal of Applied Research in Intellectual Disabilities*, *18*(1), 7–17. doi:10.1111/j.1468-3148.2004.00204.x

Bowlby, J. (1969). *Attachment and loss*. Vol. 1: Attachment. New York: Basic Books.

Bowling, M., & Keltner, B. R. (1996). Primary health care for children of mothers with intellectual limitations. *Pediatric Nursing*, *22*, 312–319.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, Massachusetts: Harvard University Press.

Bronfenbrenner, U. (2001). The bioecological theory of human development. In N. J. Smelser & P. B. Baltes (Eds.). *International encyclopedia of the social and behavioural sciences* (pp. 6963-6970). New York: Elsiver. Reprinted in U. Bronfenbrenner (2005) (Ed.). *Making human beings human*. (pp 3-15).Thousand Oaks, CA: Sage.

Bronfenbrenner, U., & Ceci, S. (1994). Nature-nurture reconceptualised in developmental perspective: A bioecological model. *Psychological Review, 101*(4), 568-586. doi:10.1037/0033-295X.101.4.568

Bronfenbrenner, U., & Croucher, A. (1983). The evolution of environmental models in developmental research. In P. Mussen (Ed.), *Handbook of child psychology, Vol 4* (pp. 357-414). New York: John Wiley and Sons.

Bronfenbrenner, U., & Morris, P. (1998). The ecology of developmental processes. In W. Damon & R. Lerner (Eds.), *Handbook of Child Psychology: theoretical*

models of human development (5th Ed.), Vol. 1, (pp. 993-1028). New York: John Wiley and Sons.

Bronfenbrenner, U. (2001). The bioecological theory of human development. Reprinted in U. Bronfenbrenner. (Ed.) (2005), *Making human beings human*. Thousand Oaks, CA: Sage.

Bronfenbrenner, U. (Ed.) (2005), *Making human beings human*. Thousand Oaks, CA: Sage

Bruner, J. (1986). *Actual minds, possible worlds.* Cambridge, MA: Harvard University Press.

Bruner, J. (1990). *Acts of Meaning.* Cambridge, MA: Harvard University Press.

Bruner, J. (1991). The narrative construction of reality. *Critical Inquiry, 18*(1), 1-21. doi: 10.1086/448619

Bruner, J., & Lucariello, J. (1989). Monologue as narrative recreation of the world. In K. Nelson (Ed.), *Narratives from the crib.* (pp 73-97). Cambridge, MA: Harvard University Press.

Bukowski, W., & Hoza, B. (1989). Popularity and friendship: Issues in theory, measurement, and outcome. In T. Berndt & G. Ladd (Eds.), *Peer relationships in child development* (pp. 15-45). New York: John Wiley and Sons.

Burman, E. (2008). Deconstructing developmental psychology (2nd ed.). East Sussex: Routledge.

Carvalho, M. J. L. (2012). Children's perspectives on disorder and violence in urban neighbourhoods. *Childhood*, *20*(1), 98 –114. doi: 10.1177/0907568212447236

Cassell, J. (2004) "We have these rules inside": The effects of exercising voice in a
children's online forum. In P. Pufall & R. Unsworth (Eds.), *Rethinking
Childhood* (pp 229-241). New Jersey: Rutgers University Press.

Castenada, C. (2002). *Figurations: child, bodies, worlds*. Durham, NC: Duke
University Press.

Chambers, R. (1994). *Participatory rural appraisal: Challenges, potentials and
paradigms*. Brighton: Institute of Development Studies.

Chawla, L. (1992) Childhood place attachment. In I. Altman & S. Low (Eds.), *Place
attachment*. New York: Plenum Press.

Chipuer, L. (2001). Dyadic attachment and community connectedness: Links with
youths' loneliness experiences. *Journal of Community Psychology*, *29*(4), 429–
446.

Christensen, P., & James, A. (2000a). Childhood diversity and commonality: Some
methodological insights. In P. Christensen & A. James (Eds.), *Research with
children: Perspectives and practices* (pp. 160-178). London: Falmer. doi
10.1177/0907568200007004003

Christensen, P., & James, A. (2000b). Researching children and childhood: Cultures
of communication. In P. Christensen & A. James (Eds.), *Research with
children: Perspectives and practices* (pp. 1-8). London: Falmer.

Christensen, P., & O'Brien, M. (2003). *Children in the City: Home, Neighbourhood
and Community*. Abingdon: Routledge.

Christenson, S., & Prout, A. (2002). Working with ethical symmetry in social research with children. *Childhood, 9*(4), 477-497. doi: 10.1177/0907568202009004007

Cillessen, A., & Mayeux, L. (2004). Sociometric status and peer group behaviour: Previous findings and current directions. In J. Kupersmidt & K. Dodge (Eds.), *Children's peer relations: From development to intervention.* Washington D.C.: American Psychological Association. doi: 10.1037/10653-001

Clandinin, J., & Connelly, M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco, CA: Jossey-Bass.

Clark, A., & Stratham, J. (2005). Listening to young children: Experts in their own lives. *Adoption and Fostering, 29*(*1*), 45-56. doi: 10.1177/030857590502900106

Clark, C. (1999). The Autodriven interview: A photographic viewfinder into children's experience. *Visual Sociology 14*, 39-50. doi: 10.1080/14725869908583801

Cleaver, H., & Nicholson, D. (2007). *Parental learning disability and children's needs: Family experiences and effective practice*. London, UK: Kingsley.

Cochran, M. M., & Davilla, V. (1992). Societal influences on children's peer relationships. In R. D. Parke & G. W. Ladd. (Eds.). *Family-peer relationships: Modes of linkage* (pp. 191-212). Hillsdale NJ: Erlbaum.

Cocks, A. (2006). The ethical maze: Finding an inclusive path towards gaining children's agreement to research participation. *Childhood, 13*(2), 247-265. doi: 10.1177/0907568206062942

Coie, J. D., & Dodge, K. A. (1983). Continuities and changes in children's social

    status: A five-year longitudinal study. *Merrill-Palmer Quarterly, 29,* 261 –

    282.

Collings, S., & Llewellyn, G. (2012). Children of parents with intellectual disability:

    Facing risks or faring okay? *Journal of intellectual and developmental*

    disability, 37(1), 65-82. doi:10.3109/13668250.2011.648610

Collins, A. (Ed.). (1984). *Development during middle childhood: The years from six*

    to twelve. Washington D.C.: National Academy Press.

Cooper, C., Coll, C., Bartko, W., Davis, H., & Chatman, C. (Eds.). (2005).

    Developmental pathways through middle childhood: Rethinking contexts and

    diversity as resources. Mahwah, NJ: Lawrence Erlbaum Associates.

Coren, E., Hutchfield, J., Thomae, M., & Gustafsson, C. (2010). Parent training

    support for intellectually disabled parents. *Campbell Systematic Reviews*, *3*, 1–

    60. doi: 10.4073/csr.2010.3

Corsaro, W. (2005). Collective action and agency in young children's peer cultures. In

    J. Qvortrup (Ed.), *Studies in modern childhood: Society, agency, culture* (pp.

    231-247). Basingstoke, Hampshire: Palgrave Macmillan.

Corsaro, W. A. (2011). *The sociology of childhood* (third ed.). Thousand Oaks,

    California: Sage Publications.

Cowan, P., & Cowan, C. (2004). From family relationships to peer rejection to

    antisocial behaviour in middle childhood. In J. Kupersmidt & K. Dodge (Eds.),

Children's Peer Relations: From Development to Intervention. Washington D.C.: American Psychological Association.

Criss, M., Pettit, G., Bates, J., Dodge, K., & Lapp, A. (2002). Family adversity, positive peer relationships, and children's externalizing behaviour: A longitudinal perspective on risk and resilience. *Child Development, 73*(4), 1220-1237. doi: 10.1111/1467-8624.00468

Danby, S., & Thorpe, K. (2006). Compatibility and conflict: Negotiation of relationships by dizygotic same-sex twin girls. *Twin Research and Human Genetics, 9*(1), 103-112. doi:10.1375/twin.9.1.103

Darbyshire, P., Macdougall, C., & Schiller, W. (2005). Multiple methods in qualitative research with children: More insight or just more? *Qualitative Research in Psychology, 5*(4), 417-436.

Davis, E., Davies, B., Cook, K., Waters, E., Gibbs, L., & Priest, N. (1999). A cross-cultural examination of barriers to social inclusion for children: A qualitative study using child-centred methods. *International Journal of Mental Health Promotion 10*(1), 43-51.

Davis, J. M., & Watson, N. (2001). Where are the children's experiences? Analysing social and cultural exclusion in 'special' and 'mainstream' schools. *Disability & Society*, *16*(5), 671–687. doi: 10.1080/09687590120070060

Demaray, M., Malecki, C., Rueger, S., Brown, S., & Summers, K. (2009). The Role of Youth's Ratings of the Importance of Socially Supportive Behaviours in the Relationship Between Social Support and Self-Concept. *Journal of Youth and Adolescence, 38*, 13-28. doi:10.1007/s10964-007-9258-3

Denzin, N., & Lincoln, Y. (Eds.). (2000). *Handbook of qualitative research* (2nd Ed.). Thousand Oaks, California: Sage Publications.

DiLalla, L. (2006). Social development of twins. *Twin Research and Human Genetics, 9*(1), 95-102. doi: 10.1375/twin.9.1.95

Dixon, C., Murray, C., & Daiches, A. (2012). A qualitative exploration into young children's perspectives and understandings of emotional difficulties in other children. *Clinical Child Psychology and Psychiatry*, *18*(1), 72 –90. doi: 10.1177/1359104511433194

Dockett, S., & Perry, B. (2011). Researching with young children: seeking assent. *Child Indicators Research, 4,* 231-247. doi: 10.1007/s12187-010-9084-0

Dowdney, L., & Skuse, D. (1993). Parenting provided by adults with mental retardation. *Journal of Child Psychology and Psychiatry*, *34*, 25–47. doi:10.1111/j.1469-7610.1993.tb00966.x

Dunn, J. (2004). *Children's friendships: The beginnings of intimacy*. Maldon MA: Blackwell.

Eccles, J. (1999). The development of children ages 6 to 14. *The Future of Children: When School Is Out 9*(2), 30–44. doi: 10.2307/1602703

Edgerton, R. B. (1967). *The cloak of competence: Stigma in the lives of the mentally retarded*. Berkeley, CA: University of California Press.

Ehlers-Flint, M. (2002). Parenting perceptions and social supports of mothers with cognitive disabilities. *Sexuality and Disability, 20*(1), 29-51. doi: 10.1023/A:1015282320460

Elliot, C. (2011). "It's junk food and chicken nuggets": Children's perspectives on 'kids' food' and the question of food classification. *Journal of Consumer Behaviour*, *10*, 133–140. doi: 10.1002/cb.360

Emerson, E. (2007). Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*, 107–113. doi:10.1002/mrdd.20144

Emerson, E., & Brigham, P. (2014). The developmental health of children of parents with intellectual disabilities: Cross sectional study. *Research in Developmental Disabilities*, *35*(4), 917-921. doi:10.1016/j.ridd.2014.01.006

Emerson, E., Graham, H., Hatton, C., & Masters Glidden, L. (2006). The measurement of poverty and socioeconomic position in research involving people with intellectual disability. International Review of Research in *Mental Retardation, 32*, 77-108. doi: 10.1016/S0074-7750(06)32003-4

Engel, S. (2000). Peeking through the curtain: Narratives as the boundary between secret and known. *Michigan Quarterly Review, 39*(2).

Engel, S. (2005). Narrative analysis of children's experience. In S. Greene & D. Hogan (Eds.), *Researching children's experience* (pp. 199-216). London: Sage.

Erath, S., Pettit, G., Dodge, K., & Bates, J. (2009). Who dislikes whom, and for whom does it matter: Predicting Aggression in middle childhood. *Social Development*, *18*(3*)*, 577-596. doi: 10.1111/j.1467-9507.2008.00497.x

Farrell, A. (Ed.). (2005). *Ethical research with children*. Berkshire, UK: Open University Press.

Fattore, T., Mason, J., & Wilson, E. (2009). When children are asked about their well-being: Towards a framework for guiding policy. *Child Indicators Research, 2*(1), 57-77. doi: 10.1007/s12187-008-9025-3

Faureholm, J. (2010). Children and their life experiences. In G. Llewellyn, R. Traustadóttir, D. McConnell & H. B. Sigurjónsdóttir. (Eds.), *Parents with intellectual disabilities: Past, present and futures* (pp. 63–78). West Sussex, UK: Wiley-Blackwell. doi:10.1002/9780470660393.

Feldman, M. (1994). Parenting education for parents with intellectual disabilities: A review of outcome studies. *Research in Developmental Disabilities, 15*(4), 299-332.

Feldman, M. A. (2002). Children of parents with intellectual disabilities. In R. J. McMahon & R. Peters (Eds.), *The effects of parental dysfunction on children* (pp. 205–223). New York, NY: Kluwer Academic/Plenum.

Feldman, M. A., Sparks, B., & Case, L. (1993). Effectiveness of home-based early intervention on the language development of children of mothers with mental retardation. *Research in Developmental Disabilities*, *14*, 387–408. doi:10.1016/0891-4222(93)90010-H

Feldman, M, Varghese, J., Ramsay, J., & Rajska, D. (2002). Relationship between social support, stress and mothers-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*, 314-323. doi: 10.1046/j.1468-3148.2002.00132.x

Feldman, M., & Walton-Allen, N. (1997). Effects of maternal mental retardation and poverty on intellectual, academic and behavioural status of school-age children. *American Journal on Mental Retardation*, *101*, 352–364.

Foley, P., Parton, N., Roche, J., & Tucker, S. (2003). Contradictory and convergent trends in law and policy affecting children in England. In C. Hallet & A. Prout (Eds.), *Hearing the Voices of Children: Social Policy for a New Century* (pp. 106- 120). London: RoutledgeFarmer.

Frones, I. (2005). Structuration of childhood: An essay on the structuring of childhood and anticipatory socialization. In J. Qvortrup (Ed.), *Studies in modern childhood: Society, agency, culture* (pp. 267- 282). Basingstoke, Hampshire: Palgrave Macmillan.

Gallagher, J., & Ramey, C. (1987). *The malleability of children.* Baltimore and London: Brooks Publishing Co.

Gallagher, K. (2002). Does child temperament moderate the influence of parenting on adjustment? *Developmental Review*, *22*, 623-643. doi: 10.1016/S0273-2297(02)00503-8

Garbarino, J., Bradshaw, C., & Kostelny, K. (2005). Neighbourhood and community influences on parenting. In T. Luster & L. Okagaki (Eds.), *Parenting: An ecological perspective* (pp. 297-318): Routledge.

Garber, H. L. (1988). *The Milwaukee project: Preventing mental retardation in children at risk*. Washington, DC: American Association on Mental Retardation. (ERIC Document Reproduction Service No. ED318183).

Garber, H. L., & Hodge, J. D. (1989). Risk for deceleration in the rate of mental development. *Developmental Review*, *9*, 259–300. doi:10.1016/0273-2297(89)90031-2

Garcia Coll, C., & Szlacha, L. (2004). The multiple contexts of middle childhood. *The Future of Children*. *14*(2), 81-97. doi: 10.2307/1602795

Gath, A. (1988). Annotation: Mentally handicapped people as parents. *Journal of Child Psychology and Psychiatry, 29*(6), 739-744. doi: 10.1111/j.1469-7610.1988.tb00750.x

Gillberg, C., & Geijer-Karlsson, M. (1983). Children born to mentally retarded women: A 1–21 year follow-up study of 41 cases. *Psychological Medicine*, *13*, 891–894. doi:10.1017/S003329170005162X

Glaun, D. E., & Brown, P. F. (1999). Motherhood, intellectual disability and child protection: Characteristics of a court sample. *Journal of Intellectual and Developmental Disability*, *24*, 95–105. doi:10.1080/13668259900033901

Goddard, J., McNameee, S., & James, A. (Eds.). (2005). *The politics of childhood: International perspectives, contemporary developments*. Basingstoke, Hampshire: Pan Macmillan.

Greene, S., & Hill, M. (2005). Researching children's experience: Methods and methodological issues. In S. Greene & D. Hogan (Eds.). *Researching children's experience: Approaches and methods.* (pp 1-21). London: Sage.

Greenspan, S., Wieder, S., Nover, R., Lieberman, A., Lourie, R., & Robinson, M. (Eds.). (1987). *Infants in multirisk families: Case studies in preventative intervention.* Madison Connecticut: International Universities Press.

Grimes, C., Klein, T., & Putallaz, M. (2004). Parents' relationships with their parents and peers: Influences on children's social development. In J. Kupersmidt & K. Dodge (Eds.), *Children's peer relations: From development to intervention.* (pp 141-158) Washington D.C.: American Psychological Association. doi: 10.1037/10653-008

Hall, J., & Powell, J. (2011). Understanding the Person through Narrative. *Nursing Research and Practice,* Volume 2011, doi:10.1155/2011/293837

Hallet, C., Murray, C., & Punch, S. (2003). Young people and welfare. In C. Hallet & A. Prout (Eds.), *Hearing the voices of children: Social policy for a new century* (pp. 123-138). London: RoutledgeFarmer.

Harden, B. J., & Whittaker, J. V. (2011). The early home environment and developmental outcomes for young children in the child welfare system. *Child and Youth Services Review*, 33(8), 1392-1403. 10.1016/j.childyouth.2011.04.009

Harden, J., Scott, S., Backett-Milburn, K., & Jackson, S. (2000). Can't talk, won't talk? Methodological Issues in researching children, *Sociological Research Online*, *5*(2). doi: 10.5153/sro.486

Hewitt, O. (2007). What is the effect on a child of having a parent with a learning disability? *Tizard Learning Disability Review*, *12*(2), 33–44. doi:10.1108/13595474200700015

Hilferty, F., Mullan, K., van Gool, K., Chan, S., Eastman, C., *et al*. (2010). *The evaluation of Brighter Futures, NSW Community Services early intervention program: Final Report*. Sydney: Social Policy Research Centre, University of New South Wales.

Hill, M. (2005). Ethical considerations in researching children's experiences. In S. Greene & D. Hogan (Eds.), *Researching children's experiences: Approaches and methods*. (pp 61-87). London: Sage.

Hill, M., Laybourn, N., & Borland, M. (1996). Engaging with primary-school aged children about their emotions and well-being: Methodological considerations. *Children and Society, 10*(1), 129- 144. doi: 10.1002/(SICI)1099-0860(199606)10:2<129::AID-CHI16>3.0.CO;2-S

Hindman, A. H., & Morrison, F. J. (2012). Differential contributions of three parenting dimensions to preschool literacy and social skills in a middle-income sample. *Merrill-Palmer Quarterly 58*(2), 191-223.   10.1353/mpq.2012.0012

Holloway, S., & Valentine, G. (2000). Spatiality and the new social studies of childhood. *Sociology*, *34*(4), 763–783. doi: 10.1177/S0038038500000468

Holstein, J., & Gubrium, J. (1997). Active interviewing. In D. Silverman (Ed.), *Qualitative research: Theory, methods and practice* (pp. 113-129). London: Sage.

Hood, S., Kelley, P., & Mayall, B. (1996). Children as research subjects: A risky enterprise? *Children and Society, 10*(2), 117-128. doi: 10.1002/(SICI)1099-0860(199606)10:2<117::AID-CHI17>3.0.CO;2-U

Huesmann, L.R., Dubow, E., Eron, L., & Boxer, P. (2006). Middle childhood family-contextual and personal factors as predictors of adult outcomes. In A. Huston & M. Ripke (Eds.), *Developmental contexts in middle childhood: Bridges to adolescence and adulthood*. (pp. 62-86). New York: Cambridge University Press.

Husby, I., Heitmann, B., & O'Doherty Jensen, K. (2008). Meals and snacks from the child's perspective: the contribution of qualitative methods to the development of dietary interventions. *Public Health Nutrition*, *12*(6), 739–747. doi: 10.1017/S1368980008003248

Huston, A., & Ripke, M. (2006). Middle childhood: Contexts and development. In A. Huston & M. Ripke (Eds.). *Developmental contexts in middle childhood: Bridges to adolescence and adulthood*. (pp 1-22). New York: Cambridge University Press

Hutchby I and Moran-Ellis J (1998). Situating children's social competence. In I. Hutchby and J. Moran-Ellis (Eds.). *Children and Social Competence: Arenas of action*. (pp 8–28) London: Falmer.

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities. (2008). Parents labelled with intellectual disability: Position of the IASSID SIRG on parents and parenting with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *21*, 296–307. doi:10.1111/j.1468-3148.2008.00435.x

Ingoldsby, E., & Shaw, D. (2002). Neighbourhood contextual factors and early-starting antisocial pathways. *Clinical Child and Family Psychology Review, 5*(1), 21-55. doi.org/10.1023/A:1014521724498

Irwin, I., Johnson, J., Henderson, A., Dahinten, V., & Hertzma, C. (2006). Examining how contexts shape young children's perspectives of health. *Child: Care, Health and Development*, *33*(4), 353-359. doi: 10.1111/j.1365-2214.2006.00668.x

James, A. (2005). Life times: Children's perspectives on age, agency and memory across the life course. In J. Qvortrup (Ed.), *Studies in modern childhood: Society, agency, culture* (pp. 248-266). Houndmills, Basingstoke, Hampshire: Palgrave Macmillan.

James, A., Jenks, C., & Prout, A. (1998). *Theorizing Childhood*. Cambridge, UK: Polity Press.

James, A., & Prout, A. (1997). A new paradigm for the Sociology of Childhood: provenance, promises and problems. In A. James & A. Prout (Eds.), *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood*. (2nd Ed., pp. 7-32). London: Falmer Press.

Jamieson, L., & Milne, S. (2012). Children and young people's relationships, relational processes and social change: reading across worlds. *Children's Geographies*, *10*(3), 265 –278. doi: 10.1080/14733285.2012.693377

Jenks, C. (1996). The conceptual limitations on a sociological approach to childhood In C. Jenks (Ed.), *Childhood* (pp. 32-55). New York: Routledge.

Jenks, C. (2000). Zeitgeist research on childhood. In P. Christensen & A. James

    (Eds.), *Research with children: Perspectives and practices* (pp. 62-76).

    London: Falmer.

Karsten, L. (2003). Children's use of public space: The gendered world of the

    playground. *Childhood*, *10*(4), 457–473. doi: 10.1177/0907568203104005

Kay, E., Tisdall, M., Davis J, & Gallagher M (Eds.). (2009). *Researching with*

    children and young people: Research designs, methods and analysis. London:

    Sage Publications.

Keltner, B. (1992). Caregiving by mothers with mental retardation. *Family*

    Community Health, 15(2), 10-18. doi: 10.1097/00003727-199207000-00005

Keltner, B., Finn, D., & Shearer, D. (1995). Effects of family intervention on

    maternal-child interaction for mothers with developmental disabilities. *Family*

    Community Health, *17*(4), 35–49. doi: 10.1097/00003727-199501000-00006

Keltner, B., Wise, L. A., & Taylor, G. (1999). Mothers with intellectual limitations

    and their 2-year-old children's developmental outcomes. *Journal of*

    Intellectual and Developmental Disability, *24*, 45–57.

    doi:10.1080/13668259900033871

Kendrick, D., Elkan, R., Hewitt, M., Dewey, M., Blair, M., Robinson, J., Williams,

    D., Brummell, K. (2000). Does home visiting improve parenting and the

    quality of the home environment? A systematic review and meta-analysis.

    Archives of Disease in Childhood, 82, 443-451. doi: 10.1136/adc.82.6.443

Killeen, M., & Coplan, R. (Eds.). (2011). *Social development in childhood and adolescence: A contemporary reader.* West Sussex: Wiley-Blackwell.

Klima, T., & Repetti, R. (2008). Children's peer relations and their psychological adjustment: Differences between close friendships and the larger peer group. *Merrill-Palmer Quarterly*, *54*(2), 151-178. doi: 10.1353/mpq.2008.0016

Kulkofsky, S., & Klemfuss, J. (2008). What the stories children tell can tell about their memory: Narrative skill and young children's suggestibility. *Developmental Psychology, 44 (*5), 1442–1456. doi: 10.1037/a0012849

Kupersmidt, J., & Dodge, K. (Eds.). (2004). *Children's peer relations: From development to intervention,* Washington D.C.: American Psychological Association. doi: 10.1037/10653-000

Ladd, G., & Troop-Gordon, W. (2003). The role of chronic peer difficulties in the development of children's psychological adjustment problems. *Child Development, 74*(5), 1344-1367. doi:10.1111/1467-8624.00611

Lamb, M., & Brown, D. (2006). Conversational apprentices: Helping children become competent informants about their own experiences. *British Journal of Developmental Psychology, 24*, 215-234. doi: DOI:10.1348/026151005X57657

Lamont, A., & Bromfield, L. (2009). *Parental intellectual disability and child protection: Key issues* NCPC Issues (pp. 1-19). Melbourne: Australian Institute of Family Studies.

Levy, F., Hay, D., McLaughlin, M., Wood, C., & Waldman, I. (1996). Twin sibling differences in parental reports of ADHD, speech, reading and behaviour problems. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 37*, 569-578. doi: 10.1111/j.1469-7610.1996.tb01443.x

Lewis, M., & Feiring, C. (1989). Early predictors of childhood friendship In T. Berndt & G. Ladd (Eds.), *Peer relationships in child development* (pp. 246-273). New York: John Wiley and Sons.

Lincoln, Y., & Guba, E. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 163-188). Thousand Oaks, California: Sage Publications.

Lindsey, E., Colwell, M., Frabutt, J., & MacKinnon-Lewis, C. (2006). Family conflict in divorced and non-divorced families: Potential consequences for boys' friendship status and friendship quality. *Journal of Social and Personal Relationships, 23*, 45-63. doi: 10.1177/0265407506060177

Little, M., Axford, N., & Morpeth, L. (2004). Research review: Risk and protection in the context of services for children in need. *Child and Family Social Work, 9*, 105-117. doi: 10.1111/j.1365-2206.2004.00296.x

Llewellyn, G. (1995). Relationships and social support: Views of parents with mental retardation/intellectual disability. *Mental Retardation, 33*(6), 349-363.

Llewellyn, G., & Gustavsson, A. (2010). Understanding community in the lives of parents with intellectual disabilities. In G. Llewellyn, R. Traustadóttir, &, D. McConnell & H.B. Sigurjónsdóttir (Eds.). *Parents with intellectual*

disabilities: Past, present and futures. Australia: John Wiley. doi: 10.1002/9780470660393

Llewellyn, G., & McConnell, D. (2002). Mothers with learning difficulties and their support networks *Journal of Intellectual Disability Research, 46*(1), 17-34. doi: 10.1046/j.1365-2788.2002.00347.x

Llewellyn, G., & McConnell, D. (2004). Mothering capacity and social milieu. In S. Esdaile & J. Olsen (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 173-192). Philadelphia: FA Davis.

Llewellyn, G., McConnell, D., & Bye, R. (1998). Perceptions of service needs by parents with intellectual disability, their friends/neighbours and their service workers. *Research in Developmental Disability, 19*(3), 245-260. doi: 10.1016/S0891-4222(98)00006-7

Llewellyn, G., McConnell, D., & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse and Neglect*, *27*, 235–251. doi:10.1016/S0145-2134(03)00004-8

Llewellyn, G., Traustadóttir, R., McConnell, D., & Sigurjónsdóttir, H.B. (Eds.). (2010). *Parents with* intellectual disabilities: Past, present and futures. West Sussex: Wiley-Blackwell. doi: 10.1002/9780470660393

Losh, M., & Capps, L. (2003). Narrative ability in high-functioning children with autism or Asperger's Syndrome. *Journal of Autism and Developmental Disorders, 33*(3), 239-251. doi:10.1023/A:1024446215446

Maas, A., Vreeswijk, C., & van Bakel, H. (2013). Effect of situation on mother-infant interaction. *Infant Behaviour and Development, 36*(1), 42-49. 10.1016/j.infbeh.2012.10.006

Magnuson, K., Duncan, G., & Kalil, A. (2006). The contribution of middle childhood contexts to adolescent achievement and behaviour. In A. Huston & M. Ripke (Eds.), *Developmental* contexts in middle childhood (pp. 150-172). New York: Cambridge University Press. doi: 10.1017/CBO9780511499760.009

Malcolm, K., Jensen-Campbell, L., Rex-Lear, M., & Waldrip, A. (2006). Divided we fall: Children's friendships and peer victimization. *Journal of Social and Personal Relationships*, *23*, 721-740. doi: 10.1177/0265407506068260

Man, W.Y., Llewellyn, G., and Wade, C. (2013). Children of parents with intellectual disability in Australia. *3rd International Association for Scientific Study of Intellectual and Developmental Disability (IASSID) Asia-Pacific conference*, 22-24 August 2013, Tokyo, Japan in *Journal of Policy and Practice in Intellectual Disabilities* 10(2): 145.

Mandell, N. (1991). The least-adult role in studying children. In F. Waksler (Ed.), *Studying the social worlds of children* (pp. 38-59). London: The Falmer Press.

Martin, S. L., Ramey C. T., & Ramey, S. (1990). The prevention of intellectual impairment in children of impoverished families: Findings of a randomized trial of educational day care. *American Journal of Public Health*, *80*, 844–847. doi: 10.2105/AJPH.80.7.844

Mayall, B. (1996). *Children, health and the social order*. Buckingham: Open University Press.

Mayall, B. (2000). Conversations with children: Working with generational issues. In P. Christensen & A. James (Eds.), *Research with children: Perspectives and practices*. London: Falmer Press.

Mayes, R., Llewellyn, G., & McConnell, D. (2006). Misconception: The experience of pregnancy for women with intellectual disabilities. *Scandinavian Journal of Disability Research*, *8*, 120–131. doi:10.1080/15017410600774178

McConnell, D., Dalziel, A., Llewellyn, G., Laidlaw, K., & Hindmarsh, G. (2009). Strengthening the social relationships of mothers with learning difficulties. *British Journal of Learning Disabilities, 37*(*1*), 66-75. doi: 10.1111/j.1468-3156.2008.00526.x

McConnell, D., Feldman, M., Aunos, M., & Prasad, N. (2010). *Child welfare process and outcomes: Caregiver cognitive impairment*. Edmonton: University of Alberta Press.

McConnell, D., & Llewellyn, G. (2000). Disability and discrimination in statutory child protection proceedings. *Disability & Society*, *15*, 883–895. doi:10.1080/713662015

McConnell, D., & Llewellyn, G. (2010). Supporting mothers' community participation. In G. Llewellyn, R. Traustadóttir, D. McConnell & H.B. Sigurjónsdóttir (Eds.), *Parents with intellectual disability: Past, present, futures* (pp. 205-224). West Sussex: Wiley-Blackwell. doi: 10.1002/9780470660393.ch13

McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003). Developmental profiles of children born to mothers with intellectual disability.

Journal of Intellectual and Developmental Disability, *28*, 122–134. doi:10.1080/1366825031000147067

McConnell, D., Matthews, J., Llewellyn, G., Mildon, R., & Hindmarsh, G. (2008). "Healthy Start". A national strategy for parents with intellectual disabilities and their children. *Journal of Policy and Practice in Intellectual Disabilities, 5*(3), 194-202. doi:10.1111/j.1741-1130.2008.00173.x

McConnell, D., Mayes, R., & Llewellyn, G. (2008). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *Journal of Intellectual Disability Research*, 52, 529–535. doi:10.1111/j.1365-2788.2008.01061.x

McGaw, S., Ball, K., & Clark, A. (2002). The effect of group intervention on the relationships of parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities 15*, 354–366. doi:10.1046/j.1468-3148.2002.00143.x

McGaw, S., Shaw, T., & Beckley, K. (2007). Prevalence of psychopathology across a service population of parents with intellectual disabilities and their children. *Journal of Policy and Practice in Intellectual Disabilities*, *4*, 11–22. doi:10.1111/j.1741-1130.2006.00093.x

Mercer, J. (1973). *Labelling the mentally retarded.* Berkeley, CA: University of California Press.

Mickelson, P. (1947). The feeble-minded parent: A study of 90 family cases. *American Journal of Mental Deficiency*, *51*, 644–653.

Mier, N., Lee, C., Smith, M., Wang, X., Irizarry, D., Avila-Rodriguez, E Trevino, L., Ory, M. (2013). Mexican-American children's perspectives: Neighbourhood characteristics and physical activity in a Texas-Mexico border colonias. *Journal of Environmental Health*, *76*(3), 8-16.

Mildon, R., Matthews, J., & Gavidia-Payne, S. (2003). *Best practice in parenting education: Understanding and supporting parents with learning difficulties.* Melbourne: Victorian Parenting Centre.

Mildon, R., Wade, C., & Matthews, J. (2008). Considering the contextual ft of an intervention for families headed by parents with an intellectual disability: An exploratory study. *Journal of Applied Research in Intellectual Disabilities, 21*, 377-387. doi:10.1111/j.1468-3148.2008.00451.x

Miller, J., & Glassner, B. (1997). The 'inside' and the 'outside': Finding realities in interviews. In D. Silverman (Ed.), *Qualitative research: Theory, method and practice* (pp. 99-112). London: Sage.

Milne, S. (2009). Moving into and through the public world: Children's perspectives on their encounters with adults. *Mobilities, 4*(1), 103–118. doi: 10.1080/17450100802657988

Mishler, E. (1995). Models of narrative analysis: A typology. *Journal of Narrative and Life History, 5*(2), 87-123.

Moore, T., Saunders, V., & McArthur, M. (2011). Championing choice- lessons learned from children and young people about research and their involvement. *Child Indicators Research, 4*, 249-267. doi: 10.1007/s12187-010-9083-1

Moran-Ellis, J. (2010). Reflections on the Sociology of Childhood in the UK. *Current Sociology 58*(2): 186-205. doi:10.1177/0011392109354241

Moran-Ellis, J & Sünker., H. (2013). Adult Trust and Children's Democratic Participation. In H. Warming (Ed.). *Participation, Citizenship and Trust in Children's Lives*. (pp 32-51). Basingstoke, U.K: Palgrave Macmillan.

Mørch, W.-T., Skår, J., & Andersgård, A. B. (1997). Mentally retarded persons as parents: Prevalence and the situation of their children. *Scandinavian Journal of Psychology, 38*, 343–348. doi:10.1111/1467-9450.00044

Morris, P., & Kalil, A. (2006). Out-of-school time use during middle childhood in a low-income sample. In A. Huston & M. Ripke (Eds.). *Developmental contexts in middle childhood: Bridges to adolescence and adulthood* (pp. 237-259). New York: Cambridge University Press. doi:10.1017/CBO9780511499760.013

Morrison, E. F., Rimm-Kaufman, S., & Pianta, R. C. (2003). A longitudinal study of mother-child interactions at school entry and social and academic outcomes in middle school. *Journal of School Psychology, 41*, 185-200. 10.1016/S0022-4405(03)00044-X

Morrow, V. (2001). Using qualitative methods to elicit young people's perspectives on their environments: Some ideas for community health initiatives. *Health Education Research 16*(3), 255-268. doi: 10.1093/her/16.3.255

Morrow, V., & Richards, M. (1996). The ethics of social research with children: An overview. *Children and Society 10*, 90-105. doi:10.1002/(SICI)1099-0860(199606)10:2<90:AID-CHI14>3.0.CO;2-Z

National Health and Medical Research Council. (2007). *National Statement on Ethical Conduct in Human Research.* (E72). Canberra: Australian Government.

Nichols, M. L. (1989). *The self-esteem of normal children of mothers with mental retardation: An exploratory study* (Unpublished doctoral dissertation). University of Oregon, Portland.

Nickerson, A., & Nagle, R. (2004). The influence of parent and peer attachments on life satisfaction in middle childhood and early adolescence. *Social Indicators Research, 66*, 35-60. doi:10.1023/B:SOCI.0000007496.42095.2c

O'Connor, T. (2002). The 'effects' of parenting reconsidered: Findings, challenges, and applications. *Journal of Child Psychology and Psychiatry, 43*(5), 555-572. doi:10.1111/1469-7610.00046

O'Kane, C. (2000). The development of participatory techniques: Facilitating children's views about decisions which affect them. In P. Christensen & A. James (Eds.), *Research with children: Perspectives and practices* (pp. 136-159). London: Falmer.

O'Neil, R., Parke, R. D., & McDowell, D. J. (2001). Objective and subjective features of children's neighbourhoods: Relations to parental regulatory strategies and children's social competence. *Applied Developmental Psychology*, 22, 135-155. doi: 10.1016/S0193-3973(01)00073-9

Oh, W., Rubin, K., Bowker, J., Booth-LaForce, C., Rose-Krasnor, L., & Laursen, B. (2008). Trajectories of social withdrawal from middle childhood to early adolescence. *Journal of Abnormal Child Psychology*, *36,* 553–566. doi: 10.1007/s10802-007-9199-z

O'Neill, A. M. (1985). Normal and bright children of mentally retarded parents: The

    Huck Finn syndrome. *Child Psychiatry and Human Development*, 15, 255–

    268. doi:10.1007/BF00706369

O'Neill, A. M. (2011). Average and bright children of parents with mild cognitive

    difficulties: The Huck Finn Syndrome 20 years later. *Journal of Applied*

    Research in Intellectual Disabilities, 24, 566-572. doi:10.1111/j.1468-

    3148.2011.00631.x

Orellana, M. (1999). Space and place in an urban landscape: Learning from children's

    views of their social worlds. *Visual Sociology*, *14*, 73-89. doi:

    10.1080/14725869908583803

Parker, J., & Asher, S. (1993). Friendship and friendship quality in middle childhood:

    Links with peer group acceptance and feelings of loneliness and social

    dissatisfaction. *Developmental Psychology, 29*(4), 611-621. doi:10.1037/0012-

    1649.29.4.611

Pearce, A., Kirk, C., Cummins, S., Collins, M., Elliman, M., Connolly, A., & Law, C.

    (2009). Gaining children's perspectives: A multiple method approach to

    explore environmental influences on healthy eating and physical activity.

    Health & Place, 15, 614–621. doi: 10.1016/j.healthplace.2008.10.007

Perkins, T. S., Holburn, S., Deaux, K., Flory, M. J., & Vietze, P. (2002). Children of

    mothers with intellectual disability: Stigma, mother–child relationships and

    self-esteem. *Journal of Applied Research in Intellectual Disabilities*, *15*, 297–

    313. doi:10.1046/j.1468-3148.2002.00140.x

Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. Albany State: University of New York Press.

Poobalan, A., Aucott, L., Ross, L., Cairns, W., Smith, S., Helms, P., & Williams, J. (2007). Effects of treating postnatal depression on mother–infant interaction and child development. *The British Journal of Psychiatry, 191,* 378-386. doi: 10.1192/bjp.bp.106.032789

Prinstein, M. J., & LaGreca, A. M. (1999). Links between mothers' and children's social competence, and associations with maternal adjustment. *Journal of Clinical Child Psychology*, *28*, 197-210. doi: 10.1207/s15374424jccp2802_7

Prout, A. (2003). Participation, policy and the changing conditions of childhood. In C. Hallet & A. Prout (Eds.), *Hearing the voices of children: Social policy for a new century* (pp. 11-25). London: Routledge Farmer.

Pulkkinen, L., Vaalamo, I., Hietala, R., Kaaprio, J., & Rose, R. (2003). Peer reports of adaptive behaviour in twins and singletons: Is twinship a risk or an advantage? *Twin Research and Human Genetics*, *6*, 106-118.

Putallaz, M., Costanza, P., & Smith, R. (1991). Maternal Recollections of Childhood Peer Relationships: Implications for their Children's Social Competence. *Journal of Social and Personal Relationships*, *8,* 403-422. doi: 10.1177/0265407591083006

Qvortrup, J. (2000). Macroanalysis of childhood. In P. Christensen & A. James (Eds.), *Research with children: Perspectives and practices* (pp. 77-97). London: Falmer.

Qvortrup, J. (2003). An established field or a breakthrough still pending? *Childhood, 10*(4), 395-400. doi: 10:1177/0907568203104001

Qvortrup, J. (2004). The waiting child. *Childhood, 11*(3). doi: 10:1177/0907568204044884

Qvortrup, J. (2005). Varieties of childhood. In J. Qvortrup (Ed.), *Studies in modern childhood: Society, agency, culture* (pp. 1-20). Houndmills, Basingstoke, Hampshire: Palgrave Macmillan. doi:10.1057/9780230504929

Rabaglietti, E., Vacirca, M. F., Zucchetti, G., & Ciairano, S. (2012). Similarity, cohesion, and friendship networks among boys and girls: A one-year follow-up study among Italian children. *Current Psychology*, *31*, 246–262. doi: 10.1007/s12144-012-9145-2

Ramey, C., & Campbell, F. (1984). Preventive education for high-risk children: Cognitive consequences of the Carolina Abecedarian Project. *American Journal of Mental Deficiency*, *88*, 515–523.

Ramey, C., & Campbell, F. (1987). The Carolina Abecedarian Project: An educational experiment concerning human malleability. In J. Gallagher & C. Ramey (Eds.). *The malleability of children* (pp. 127–139). Baltimore, MD: Brookes.

Ramey, C., & Ramey, S. (1994). Which children benefit most from early intervention? *Pediatrics, 94*(6), 1064-1066.

Ramey, C., & Ramey, S. L. (2004). Early learning and school readiness: Can early intervention make a difference? *Merrill-Palmer Quarterly*, *50*, 471–491. doi:10.1353/mpq.2004.0034

Rasmussen, K. (2004). Places for children, children's places. *Childhood*, *11*(2), 155–173. doi: 10.1177/0907568204043053

Ridge, T. (2007). It's a family affair: Low-income children's perspectives on maternal work. *Journal of Social Policy*, *36*(3), 399 - 416. doi: 10.1017/S0047279407001109

Riessman, C. K. (2008). *Narrative methods for the human sciences.* Thousand Oaks, California: Sage Publications.

Ripke, M., Huston, A., Eccles, J., & Templeton, J. (2008). The assessment of psychological, emotional, and social development indicators in middle childhood. In B. Brown (Ed.), *Key indicators of child and youth well-being* (pp. 131-166). New York: Taylor and Francis.

Roberts, H. (2000). Listening to children: And hearing them. In P. Christensen & A. James (Eds.), *Research with children: Perspectives and practices* (pp. 225-240). London: Falmer.

Rodkin, P., Ryan, A., Jamison, R., & Wilson, T. (2013). Social goals, social behaviour, and social status in middle childhood. *Developmental Psychology, 49*(6), 1139–1150 doi: 10.1037/a0029389.

Rogers, M. (2013). "They are there for you": The Importance of neighbourhood friends to children's well-being. *Child Indicators Research, 5*, 483–502. doi: 10.1007/s12187-012-9146-6

Ronai, C. R. (1997). On loving and hating my mentally retarded mother. *Mental Retardation*, *35*, 417–432. doi:10.1352/0047-6765(1997)035<0417:OLAHMM>2.0.CO;2

Rubin, K., Bukowski, W., & Parker, J. (2006a). Peer interactions, relationships, and groups. In Eisenberg N & Lerner R (Eds.), *Handbook of child psychology*: *Vol. 3. Social, emotional, and personality development* (6th ed., pp. 571–645). Hoboken, NJ: Wiley.

Rubin, K., & Coplan, R. (2004). Paying attention to and not neglecting social withdrawal and social isolation. *Merril-Palmer Quarterly*, *50*(4).

Rubin, K., Wojslawowicz, J., Rose-Krasnor, L., Booth-LaForce, C., & Burgess, K. (2006b). The best friendships of shy/withdrawn children: Prevalence, stability, and relationship quality. *Journal of Abnormal Child Psychology*, 34(*5*), 143–157 doi: 10.1007/s10802-005-9017-4

Sandstrom, M., & Zakriski, M. (2004). Understanding the experience of peer rejection. In J. Kupersmidt & K. Dodge (Eds.) *Children's Peer Relations: From Development to Intervention*. Washington D.C.: American Psychological Association.

Schmidt, M., & Bagwell, C. (2007). The protective role of friendships in overtly and relationally victimized boys and girls. *Merrill-Palmer Quarterly*, *53*(3), 439-460. doi: 10.1353/mpq.2007.0021

Schneider, B., Atkinson, L., & Tardif, C. (2001). Child-parent attachment and children's peer relations: A quantitative review. *Developmental Psychology, 37*, 86-100. doi: /10.1037/0012-1649.37.1.86

Schwartz, D., Hopmeyer Gorman, A., Duong, M., & Nakamoto, J. (2008). Peer
relationships and academic achievement as interacting predictors of depressive
symptoms during middle childhood. *Journal of Abnormal Psychology, 117*(2),
289–299 doi: 10.1037/0021-843X.117.2.289.

Schweinhart, L., & Weikart, D. (1980). *Young children grow up: The effects of the
Perry Preschool Program on youths through to age 15*. Ypsilanti, Michigan:
The High/Scope Press.

Scott, J. (2000). Children as respondents: The challenge for quantitative methods. In
P. Christensen & A. James (Eds.), *Research with children: Perspectives and
practices* (pp. (98-120). London: Falmer.

Scourfield, J., Dicks, B., Holland, S., Drakeford, M., & Davies, A. (2006). The
significance of place in middle childhood: Qualitative research from Wales.
The British Journal of Sociology. 57(4), 577-595.

Seagull, E. A. W., & Scheurer, S. L. (1986). Neglected and abused children of
mentally retarded parents. *Child Abuse & Neglect, 10*, 493–500.
doi:10.1016/0145-2134(86)90054-2

Seibert, A., & Kerns, K. (2009). Attachment figures in middle childhood.
International Journal of Behavioural Development, 33(4), 347–355.
doi:10.1177/0165025409103872

Shannon, C. (2013). *Juvenile Incarceration and re-entry: A Photovoice study.* El
Paso: LFB Scholarly Publishing.

Shiavo, R. S. (1988). Age differences in assessment and use of a suburban neighbourhood among children and adolescents. *Children's Environment Quarterly 5* (2), 4-9.

Sigurjónsdóttir, H. B,. & Traustadóttir, R. (2010). A family within a family. In G. Llewellyn, R. Traustadóttir, D. McConnell & H. B. S Sigurjónsdóttir (Eds.), *Parents with intellectual disability: Past, present, futures* (pp. 49-62). West Sussex: Wiley-Blackwell. doi:10.1002/9780470660393.ch3

Silverman, D. (2000). Analysing talk and text. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 821-834). Thousand Oaks, California: Sage Publications.

Simpkins, S., & Parke, R. (2001). The relations between parental friendships and children's friendships: Self-report and observational analysis. *Child Development*, *72*(2), 569-582. doi:10.1111/1467-8624.00297

Sperry, L., & Sperry, D. (1996). Early development of narrative skills. *Cognitive Development, 11,* 443-465. doi:10.1016/S0885-2014(96)90013-1

Spilsbury, J., Korbin, J., & Coulton, C. (2009). Mapping children's neighbourhood perceptions: Implications for child indicators. *Child Indicators Research*, *2*(2), 111-131.

Spyro, S. (2011). The limits of children's voices: From authenticity to critical, reflexive representation. *Childhood, 18*(2), 151-165. doi:10.1177/0907568210387834

Stenfert-Kroese, B., Hussein, H., Clifford, C., & Ahmed, N. (2002). Social support

 networks and psychological well-being of mothers with intellectual

 disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*, 324-

 340. doi:10.1046/j.1468-3148.2002.00128.x

Stipek, D. (2005). Children as unwitting agents in their developmental pathways. In C.

 Cooper, C. Garcia Coll, T. Barko, H. Davis & C. Chatman (Eds.),

 Developmental pathways through middle childhood (pp. 99-120). Mahwah NJ:

 Lawrence Erlbaum.

Stoeckli, G. (2010). The role of individual and social factors in classroom loneliness.

 The Journal of Educational Research, *103*, 28–39. doi:

 10.1080/00220670903231169

Strack, R., Magill, C., & McDonagh, K. (2004). Engaging Youth through Photovoice.

 Health Promotion Practice, 5(1), 49-58. doi:10.1177/1524839903258015

Taylor, C. G., Norman, D. K., Murphy, J. M., Jellinek, M., Quinn, D., Poitrast, F. G.,

 & Goshko, M. (1991). Diagnosed intellectual and emotional impairment

 among parents who seriously mistreat their children: Prevalence, type, and

 outcome in a court sample. *Child Abuse and Neglect*, *15*, 389–401.

 doi:10.1016/0145-2134(91)90023-7

Thorpe, K. (2003). Twins and friendship. *Twin Research 6*, 532-535.

 doi:10.1375/twin.6.6.532

Thorpe, K., & Danby, S. (2006). Compromised or competent: Analyzing twin

 children's social worlds. *Twin Research and Human Genetics, 9*(1), 90-94.

 doi:10.1375/twin.9.1.90

Thorpe, K., & Gardner, K. (2006). Twins and their friendships: Differences between monozygotic, dizygotic same-sex and dizygotic mixed-sex pairs. *Twin Research and Human Genetics, 9*(1), 155-164. doi:10.1375/twin.9.1.155

Tietjen, A. (1989). The ecology of children's social support networks. In D. Belle (Ed.), *Children's social networks and social support* (pp. 37-69). New York: John Wiley and sons.

Traustadóttir, R., & Sigurjónsdóttir, H. B. (2005). Adult children of mothers with intellectual disabilities: Three life histories. In A. Gustavsson, J. Sandrin, R. Traustadóttir, & J. Tøssebro (Eds.), *Resistance, reflections and change: Nordic disability research* (pp. 147–161). Lund, Sweden: Studentlitteratur.

Traustadóttir, R., & Sigurjónsdóttir, H. B. (2008). The 'mother' behind the mother: Three generations of mothers with intellectual disabilities and their family support networks. *Journal of Applied Research in Intellectual Disabilities, 21*, 331-340. doi:10.1111/j.1468-3148.2008.00450.x

Troop-Gordon, W., & Kopp, J. (2011). Teacher–child relationship quality and children's peer victimization and aggressive behaviour in late childhood. *Social Development*, *20*(3), 536-561. doi: 10.1111/j.1467-9507.2011.00604.x

Tucker, B., & Johnson, O. (1989). Competence promoting vs. competence inhibiting social support for mentally retarded mothers. *Human Organisations, 48*(2).

Tudge, J., Mokrova, I., Hatfield, B., & Karnik, R. (2009). Uses and misuses of Bronfenbrenner's bioecological theory of human development. *Journal of Family Theory & Review, 1*, 198–210. doi:10.1111/j.1756-2589.2009.00026.x

Tymchuk, A. J. (2001). Family life: Experiences of people with mild cognitive

limitations. In A. J. Tymchuk, K. C. Lakin, & R. Luckasson (Eds.), *The*

forgotten generation: The status and challenges of adults with mild cognitive

limitations (pp. 249–274)*.* Baltimore, MD: Brookes.

Tymchuk, A. J., & Andron, L. (1990). Mothers with mental retardation who do or do

not abuse or neglect their children. *Child Abuse and Neglect*, *13*, 313–323.

doi:10.1016/0145-2134(90)90003-C

Uhlendorff, H. (2000). Parents' and children's friendship networks. *Journal of Family*

Issues, 21, 191-204. doi: 10.1177/019251300021002003

UN General Assembly. *Convention on the Rights of the Child*. (Enforced 2 September

1990). UNGA Treaty Series vol. 1577, p. 3, No. 27531 art 49, retrieved at

http://treaties.un.org/Pages/ViewDetails.aspx?mtdsg_no=IV-

11&chapter=4&lang=en

UN General Assembly. *Universal Declaration of Human Rights.* (Adopted 10

December 1948) UNGA Res 217 A (III) (UDHR) art 5, retrieved at

http://www.un.org/en/documents/udhr/index.

Van Abbema, D., & Bauer, P. (2005). Autobiographical memory in middle childhood:

Recollections of the recent and distant past. *Memory, 13*(8), 829-845. doi:

DOI:10.1080/09658210444000430

Veale, A. (2005). Creative methodologies in participatory research with children. In S.

Greene & D. Hogan (Eds.), *Researching children's experience: Approaches*

and methods (pp. 253-272). London: Sage.

Vortruba-Drzal, E. (2006). Economic disparities in middle childhood development: Does income matter? *Developmental Psychology 42*(6), 1154–1167. doi: 10.1037/0012

Wade, C., Llewellyn, G., & Matthews, J. (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *21*, 351–366. doi:10.1111/j.1468-3148.2008.00449.x

Wade, C., Llewellyn, G., & Matthews, J. (2011). Modelling contextual influences on parents with intellectual disabilities and their children. *American journal on intellectual and developmental disabilities, 116*(6), 419-437. doi: 10.1352/1944-7558-116.6.419.

Walker, J., Crawford, K., & Taylor, F. (2008). Listening to children: gaining a perspective of the experiences of poverty and social exclusion from children and young people of single-parent families. *Health and Social Care in the Community*, *16*(4), 429–436. doi: 10.1111/j.1365-2524.2008.00781.x

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education and Behaviour, 24*(3), 369-387. doi:10.1177/109019819702400309

Wang, C., Kun, Yi W, Wen, Tao Z., & Carovano, K. (1998). Photovoice as a participatory health promotion strategy. *Health Promotion International, 13*(1), 75-86. doi:10.1093/heapro/13.1.75

Ward, L., & Tarleton, B. (2007). Sinking or swimming? Supporting parents with
learning disabilities and their children. *Tizard Learning Disability Review*,
12(2), 22–32. doi:10.1108/13595474200700014

Weikart, D. P., Deloria, D., Lawser, S., & Wegerink, R. (1970). *Longitudinal results
of the Ypsilanti Perry Preschool Project*. Ypsilanti, MI: HighScope
Educational Research Foundation.

Weisner, D. (2008). The Urie Bronfenbrenner top 19: Looking back at his
bioecological perspective. *Mind, Culture and Activity, 15,* 258–262. doi:
10.1080/10749030802186785

Westcott, H., & Littleton, K. (2005). Exploring meaning in interviews with children.
In S. Greene & D. Hogan (Eds.), *Researching children's experiences:
Approaches and m*ethods (pp. 142-157). London: Sage.

Willenberg, L., Ashbolt, R., Holland, D., Gibbs, L., MacDougall, C., Garrard, J.,
Green, J., Waters, E. (2010). Increasing school playground physical activity: A
mixed methods study combining environmental measures and children's
perspectives. *Journal of Science and Medicine in Sport, 13*, 210–216. doi:
10.1016/j.jsams.2009.02.011

Wilson, S., McKenzie, K., Quayle, E., & Murray, G. (2013). A systematic review of
interventions to promote social support and parenting skills in parents with an
intellectual disability. *Child: Care, Health and Development*.
doi:10.1111/cch.12023

Wise, L. (1997). *Low Income mothers with and without intellectual disability: Interactions in contextual environments*. (Unpublished doctoral thesis). University of Alabama, Birmingham.

Wojslawowicz Bowker, J., Rubin, K., Burgess, K., Booth-LaForce, C., & Rose-Krasnor, L. (2006). Behavioural characteristics associated with stable and fluid best friendship patterns in middle childhood. *Merrill-Palmer Quarterly*, *52*(4*)*, 671–693. doi: 10.1353/mpq.2006.0000

Woodhead M. (1996). In search of the rainbow: pathways to quality in large-scale programmes for young disadvantaged children. *Early Childhood Development: Practice and Reflections* (Vol. 10). The Hague: Bernard van Leer Foundation.

Woodhouse, B. (2004). Re-Visioning rights for children. In P. Pufall & R. Unsworth (Eds.), *Rethinking Childhood* (pp 229-241). New Jersey: Rutgers University Press.

Woodhead, M., & Faulkner, D. (2000). Subjects, objects or participants? In P. Christensen & A. James (Eds.), *Research with children: Perspectives and practices* (pp. 9-35). London: Falmer Press.

Yardley, C. (2011). Children as experts in their own lives: Reflections on the principles of creative collaboration. *Child Indicators Research, 4*, 191-204. doi:10.1007/s12187-010-9102-2

Zeiher, H. (2003). Shaping daily life in urban environments. In P. Christensen & M. O'Brien (Eds.). *Children in the City: Home, Neighbourhood and Community* (pp. 66-81). Abingdon: Routledge.

Zigler, E., & Hodapp, R. M. (1986). *Understanding mental retardation*. Cambridge,

UK: Cambridge University Press.

APPENDIX A: ETHICAL APPROVAL & MODIFICATION APPROVALS

The University of Sydney

11 July 2008

Professor G Llewellyn

Faculty of Health Sciences

Cumberland Campus – C42

The University of Sydney

Dear Professor Llewellyn

I am pleased to inform you that the Human Research Ethics Committee (HREC) at its meeting on 9th July 2008 approved your protocol entitled *Risk status and resilience in families with parents with intellectual disability: parents' and children's experiences, policy and public discourse*

Details of the approval are as follows:

Ref No.:   *07-2008/11006*

Approval Period: *July 2008 to July 2009*

Authorised Personnel: *Professor G Llewellyn*

                                  Ms. G. Hindmarsh

                                  Dr. R. Mayes

The HREC is a fully constituted Ethics Committee in accordance with the *National Statement on Ethical Conduct in Research Involving Humans-March 2007* under *Section 5.1.29*

The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Research Involving Humans.* We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

<u>Chief Investigator / Supervisor's responsibilities to ensure that:</u>

(1)   All serious and unexpected adverse events should be reported to the HREC as soon as possible.

(2)   All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

(3)   The HREC must be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:-

- If any of the investigators change or leave the University.

- Any changes to the Participant Information Statement and/or Consent Form.

(4)   All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement. *Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@usyd.edu.au (Email).*

(5)   Copies of all signed Consent Forms must be retained and made available to the HREC on request.

(6)   It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

(7)   The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.

(8)   A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely

Professor D I Cook

Chairman, Human Research Ethics Committee

cc: Ms. G. Hindmarsh, Faculty of Health Sciences, Cumberland Campus –
C42,   The University of Sydney

          Dr. R. Mayes, Faculty of Health Sciences, Cumberland Campus –
C42,   The University of Sydney

Encl. Approved Participant Information Sheet - Parent

        Approved Participant Information Sheet - Child

        Approved Consent Form – Parent

        Approved Interview Questions

        Approved Safety Policy

THE UNIVERSITY OF
SYDNEY

HUMAN RESEARCH ETHICS COMMITTEE
REQUEST FOR MODIFICATION

1.   **Principal Investigator:**   Prof. Gwynnyth Llewellyn

     Department: Faculty of Health Sciences

     Address: A Block, PO Box 170, Lidcombe, NSW 1825

2.   **Project Title:**   Risk status and resilience in families with parents with intellectual disability: Parents and children's experiences, policy and public discourse

3.   **HREC Approval No.:**   07-2008/11006

4.   **Names of Students/Co-Investigators:** Ms Gabrielle Hindmarsh; Dr Rachel Mayes; Ms Susan Collings

5.   **Project Description:**
     Please provide a one paragraph lay summary of your original project

Little research has been undertaken on the life experiences of children of parents with learning difficulties. This project will investigate child and parent experiences of living under the real or implied threat of child removal are at greater risk of growing up with someone other than their parents than any other group in the community. International studies report up to one in three of these children will be removed from their parents' care. Little is known about the effects this vulnerability has on the children, their parents and families, and on public policy and discourse about these children. This pilot study aims to explore the perceptions of the children, their parents and information in the public domain on the processes surrounding a child protection notification. Important issues will be highlighted for further investigation in a larger follow up study.

6.   **Any previously approved minor amendments?**   ☒ Yes   ☐ No
     If YES, please briefly outline

1. Study 1: Request for continuation of approval for 12 months (i.e. until July 2010).
2. Study 2: Request permission to recruit parents with intellectual disabilities whose children have been removed via the Women's Activities and Self Help (WASH) House, Mt Druitt.

7.   **Nature of and reasons for amendment(s)**
     Please provide details of the changes you propose to make to the project and explain why they are necessary. Please justify any increase in sample size.

Study 1: Change to the age of children from 3-10 years to 8-12 years. A narrower age range enables the study to focus on school life and friendship for middle school-age children. This group accesses different forms of social support and community based resources to pre-school age children. Literature suggests primary school-age children may also be more exposed such risks as bullying and stigma than younger children (see below references)
   1.   Perkins T, Holburn, S Deaux, K & Flory M. (2002). Children of Mothers with Intellectual Disability: Stigma, Mother-Child Relationships and Self-esteem. *Journal of Applied Research in Intellectual*
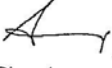
Modification Form

1. *Disabilities, 15,* 297-313.
2. Faureholm J (2010). Children and their Life Experiences in G Llewellyn, R Traustdottir, D McConnell, HB Sigurjonsdottir (Eds.) *Parents with Intellectual Disabilities: Past, Present and Futures* Sydney (p 63-78), West Sussex: Wiley Blackwell.

8. Adding New Staff Member / Student / Research Assistant ☒
Yes ☐ No

If YES, provide the following (*If more than one, please copy this page*)

Name	Susan Collings
Title: (e.g: Mr, Ms, Dr, Associate Professor)	Ms
Faculty/Department/School/Centre/Institution	Faculty of Health Sciences
Address	A Block, PO Box 170, Lidcombe, NSW 1825
Telephone Number	93519484
Facsimile Number	9351 9468
Email Address	Susan.collings@sydney.edu.au
Position (ie lecturer, PhD student)	Research associate
Qualifications (if PhD indicate field of study)	Master of Public Health
Role in the project	Co-investigator
Has the new staff member received a copy of the approved application?	☒ Yes ☐ No
Signature of new staff member	Signature **Susan Collings** Print Name ___26___ / _07___ / ____2010__ Date

9. Removing Staff Member / Student / Research Assistant ☐
Yes ☒ No

If YES, provide the following (*If more than one, please copy this page*)

Name	
Faculty/Department/School/Centre/Institution	
Position (ie lecturer, PhD student)	
Role in the project	
Date of Departure	_____ / _____ / _____

10. Possible inconveniences or risks to subjects: ☐
Yes ☒ No

If Yes, please outline any inconvenience or possible risks that the changes you propose may create for participants (eg changes to confidentiality provisions, physical or psychological risks, increased time commitments etc).

Information and consent forms (attached)

Additions: Parent Consent Form
- New University of Sydney logo
- Updated Ethics contact details- I am aware that I can contact the Manager, Human Ethics Administration, University of Sydney on + 612 8627 8176 (Telephone); + 61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au if I have any complaints at any time.
- Added name of additional researcher (S.Collings now responsible for Study 1)
- I freely choose to participate in Stage 2 of this project. I understand this project is not taking place until a later time.
- My child (name) _____ has given their verbal consent to be involved in Stage 1 of the research and I am happy for the researcher to talk to my child.
- I do not want my child to be involved in Stage 1 of this research AND/OR my child does not wish to participate in this research.
- I freely allow my child to take photographs as part of this project.

Additions: Parent information Form

- There are two stages to the study. In stage 1, we would like to talk to your child about your family and what life is like for your family. We would like to talk to one of your children (aged 8 – 12 years) about their life and their family. We are interested in what your child thinks about any other support people involved with your family. In stage 2, we would like to talk to you about your family and what life is like for your family. In particular we are interested in your experiences with child protection or other support services you or your children might be receiving.
- Stage 1 will commence in 2010. Stage 2 will commence in 2011.
- She will ask your child to take photographs of things that are important to them and they will also get a chance to draw pictures and play music that means something to them. Susan will talk to your child about their family, friends and community. You are welcome to be with your child while Susan talks to them or your family case worker can attend in your place if you prefer.
- You do not have to give permission for your child to participate in Stage 1. You can agree to participate in Stage 2, but refuse to let your child participate in Stage 1. Or you can allow your child to participate in Stage 1, but not participate yourself in Stage 2. If you decide to let your child participate you can stop their participation at any time.
-
  Updated Ethics contact details - Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on + 612 8627 8176 (Telephone); + 61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

Additions: Child Information Form
- If you are happy to help her, she will come and see you at home and meet your mum or dad so they can also find out about the research. Susan will give you a disposable camera so you can take some photos of things and people that mean something to you. Your family case worker will collect the camera when you've finished. After that, Susan can either come back to your home or you could meet somewhere like the Burnside Family Centre. She will give you your photos and will probably spend about an hour talking to you. Someone like your family case worker can stay with you the whole time you're talking to Susan if you like. Susan will ask you if it's okay if she tape-records your conversation, but won't unless you say that's ok.
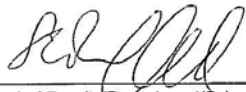
Deletions: Parent Consent Form

- Deleted outdated ethics contact details- I am aware that I can phone the University of Sydney Ethics Committee on ph: (02)9351 4811, if I have any complaints at any time.
- I freely choose to participate in this project.
- My child (name) _____ has given their verbal consent to be involved in the research and I am happy for the researcher to talk to my child.
- I do not want my child to be involved in this research AND/OR my child does not wish to participate in this research.

Deletions: Parent Information Form
- All references to 'Gabrielle Hindmarsh' (who is no longer responsible for Study 1)
- We would like to talk to one of your children aged 3-10 years
- We would like to talk to you and your child about your family and what life is like for your family. In particular

Modification Form

_____   Date: 9/8/2010

Signature of Head of Faculty/Department/School:

Convenor, Community & Disability
Faculty Research Group

Modification Form

HUMAN RESEARCH ETHICS COMMITTEE
REQUEST FOR MODIFICATION

PROJECT DETAILS

1. **Chief Investigator**: Professor Gwynnyth Llewellyn

2. **Faculty**:   Health Sciences

3. **Discipline/School**: Disability & Community Faculty Research Group

4. **Address**:   Centre for Disability Research and Policy
Faculty of Health Sciences
University of Sydney
PO Box 170
Lidcombe NSW 1825

5. **Email address:**   gwynnyth.llewellyn@sydney.edu.au

6. **Phone number:**   (02) 9351 9985

HREC Approval Number: 11006

7. **Project Title**:   Risk status and resilience in families with parents with intellectual disability: Parents' and children's experiences, policy and public discourse

TYPE OF MODIFICATION

8. **Please indicate below what type of modification you are requesting and complete the indicated sections**.

   ☒   Addition/removal of researchers (*complete sections A and E*)

   ☐   Addition of title to HREC database (*complete sections B and E*)

   ☒   Extension of HREC approval (*complete sections C and E*)

   ☐   Other modifications (*complete sections D and E*)

SECTION A - ADDITION/REMOVAL OF RESEARCHERS

9. **Removing Staff Member / Student / Research Assistant**   ☒ Yes ☐ No
If YES, provide the following (*If more than one, please copy this table and attach below*)

Name:	Gabrielle Hindmarsh
Title: (e.g: Mr, Ms, Dr, Associate Professor)	Ms
Faculty:	Health Sciences
Discipline/Department:	Disability and Community Faculty Research Group

Position (ie lecturer, PhD student):	Research Associate
Role in the project:	Co-investigator
Date of Removal:	31/8/12

10. Adding New Staff Member / Student / Research Assistant[1]   ☐ Yes ☒No

If YES, provide the following (*If more than one, please copy this table and attach below*)

Name:	
Title: (e.g: Mr, Ms, Dr, Associate Professor)	
Faculty:	
Discipline/Department:	
Address:	
Telephone Number:	
Email Address:	
Position (ie lecturer, PhD student):	
Qualifications (if PhD indicate field of study):	
Role in the project:	
Has the new staff member received a copy of the approved application (including any current conditions of approval and any existing approved amendments)?	☐ Yes ☐ No
Signature of new staff member / student / research assistant. By signing this form, the new staff member / student / research assistant (a) acknowledges receiving and reading a copy of the approved application; and (b) agrees to be bound by the approved application (including any current conditions of approval and any existing approved amendments)	*Signature* *Print Name* Date:

SECTION B - ADDITION OF TITLE TO HREC DATABASE

11. Please provide details of the additional title to be added to the HREC Database

Title:

Granting Body:

---

[1] Such an addition is not effective until HREC approval is obtained

SECTION C - EXTENSION OF HREC APPROVAL

12. What is the proposed new finishing date? 31 March 2013

13. Please provide a reason for the requested time extension

> The extension is requested for **study 1 only**: This study examines the experiences of children of parents with intellectual disability. The reasons for the extension are as follows: the co-researcher undertaking this study, Susan Collings, did not commence doctoral research until July 2009, so there was a 12 month delay after original approval was granted before the study commenced. As advised in a modification request in 2010, the proposed recruitment strategy did not result in sufficient numbers of children being recruited to the study. This also delayed the study progressing. A modified recruitment strategy was approved and seven children had been recruited by November 2011. All interviews were completed by March 2012 and data is currently under analysis. This extension will enable analysis of results to be completed and the study to be finalised by March 2013.

SECTION D - OTHER MODIFICATIONS

14. Project Description:
Please provide a one paragraph lay summary of your original project

> Little research has been undertaken on the life experiences of children of parents with intellectual disability **Study 1** will address this research gap. International studies report up to one in three of these children will be removed from their parents' care. Little is known about the effects this vulnerability has on the children, their parents and families, and on public policy and discourse about these children. **Studies 2 and 3 addressed these research gaps**. **Study 1** aims to explore the perceptions of the children, their parents and information in the public domain on the processes surrounding a child protection notification. Important issues will be highlighted for further investigation in a larger follow up study. There is an accompanying completed Annual Report Form. **Studies 2 and 3 are completed and described in the Annual Report Form.**

15. Have you had any previously approved minor amendments?　　　　　☒ Yes ☐ No
If YES, please briefly outline

> **Study 1** requested the following changes in 2010:
> 1) Add co-investigator, Susan Collings;
> 2) Expand recruitment strategy;
> 3) Change age of participants from 3-10 years to 8-12 years (middle childhood);
> 4) Modify consent and participant information forms.
> 　　　A request for modification of ethics approval was approved 17/8/10.

16. Nature of and reasons for amendment(s)
Please provide details of the changes you propose to make to the project and explain why they are necessary. Please justify any increase in sample size.

> No further modifications requested

17. Will these changes result in possible inconveniences or risks to subjects?　　　☐ Yes ☒ No
If Yes, please outline any inconvenience or possible risks that the changes you propose may create for participants (eg changes to confidentiality provisions, physical or psychological risks, increased time commitments etc).

18. Will actions be taken by researchers to reduce risks? ☐ Yes ☒ No
If Yes, please provide details of any additional actions and / or support that you will need to provide to participants as a result of the proposed changes.

19. What is the expected date of implementation of amendments to research:

Date:

20. Will funding arrangements for the research be affected by the changes? ☐ Yes ☒ No
If Yes, please provide details

21. Are there any implications for compliance with legislative requirements? ☐ Yes ☒ No
Please check current legislation and related requirements, if appropriate – including, for example, Privacy Act 1998 (please refer to Guidelines under Section 95 of the Privacy Act produced by the NHMRC) and Children and Young Persons Act 1989.

If Yes, please provide details

22. Are there changes to surveys, questionnaires or interview questions? ☐ Yes ☒ No
If yes, please attach copies of amended surveys, questionnaires or interview questions

23. Are there changes to advertisements, participant information statements or consent forms or safety protocols?
☐ Yes ☒ No

If yes, please attach copies of the amended advertisements, participant information statements and consent forms.

Note: Participants need to be advised of changes to procedures, time commitments, etc. You will need to update the participant information statement to reflect the changes

24. Will additional permissions or approvals be required as a result of your proposed changes?
☐ Yes ☒ No

If yes, please provide details

284
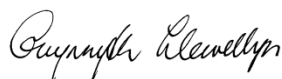
SECTION E

25. Declaration of Researchers

I confirm that this project has been conducted as originally approved by Sydney University HREC (and subject to any changes made subsequent to approval)

I confirm that the above information is accurate, and that the project will continue in accordance with the HREC approved protocol, any approved amendments and in compliance with the NHMRC National Statement on Ethical Conduct in Human Research (NHMRC, 2007)

Signature of Chief Investigator

Date: 3rd September 2012

Signature of Head of Faculty/School

Date: 3rd September 2012

NOTE:

- All Modification Requests require the signature of Head of Faculty/School except where the request is ONLY to add/remove a researcher/s.

- The Modification Request will not be processed without the signature of Head of Faculty/School

PLEASE FORWARD A SOFT COPY OF THE COMPLETED FORM AND ATTACHMENTS TO:
Email: ro.humanethics@sydney.edu.au

APPENDIX B: PARENT INFORMATION SHEET

THE UNIVERSITY OF SYDNEY

Australian Family & Disability Studies

Research Collaboration

Risk status and resilience in families with parents with intellectual disability project

Project team: Professor Gwynnyth Llewellyn

                      Ms Gabrielle Hindmarsh

                      Dr Rachel Mayes

                      Ms Susan Collings

You are invited to take part in a research project. This project is about understanding the daily family lives of parents and children and is being conducted by researchers at The University of Sydney. There are two stages to the study.

In stage 1, we would like to talk to one of your children (aged 7 – 12 years) about their friends and family. We are interested in what your child thinks about the support your family receives and their social lives. Stage 1 will commence in 2010

In stage 2, we would like to talk to you about what life is like for your family. In particular we are interested in your experiences with child protection or other support services you or your children might be receiving. Stage 2 will commence in 2011

What does participation involve for me?

If you agree, you will be asked to participate in an interview. Rachel Mayes from the research team will conduct the interview. This will take approximately one hour. We could talk at your home or any place you would like. We could talk in private or you can ask a friend to be there. Rachel will ask you about your experiences as a parent,

including your involvement with support services, such as child protection services, how you feel about them, what is good and not so good about these services, and how these affect your daily life. Rachel will also ask you if it's OK to tape-record the interview conversation.

What does participation involve for my child?

If you agree, Susan Collings from the research team will visit your child. Susan will explain the research project to your child and ask him/her if s/he would like to participate. Even if you give permission for your child to participate, they can say no if they don't want to be involved. Susan wants to know what your child thinks about what makes them resilient. Resilience means being able to 'bounce back' if something changes or goes wrong. She will ask your child to take photographs of things that are important to them but they don't have to take photographs if they don't want to. They will get a chance to draw pictures and Susan will talk to them about their family, friends and community. You are welcome to be with your child while Susan talks to them or your family case worker can attend in your place if you prefer. The photographs your child takes will not be distributed and they will receive an album of their photos as a memento.

Do I have to participate in this project?

Participation is voluntary. If you decide to take part, you or your child do not have to answer any questions that you do not want to answer. You or your child can also stop being part of the project at any time you want to. Whether you or your child take part in the project or not, any services or support you are now receiving will not be affected.

Do I have to agree to my child participating?

You do not have to give permission for your child to participate in Stage 1. You can

agree to participate in Stage 2, but refuse to let your child participate in Stage 1. Or

you can allow your child to participate in Stage 1, but not participate yourself in Stage

2. If you decide to let your child participate you can stop their participation at any

time.

Will anyone else know what I said?

Anything you or your child tells the researchers will be kept strictly confidential. We
will not share any information about you or your child unless you tell us something
that makes us worry about your or your child's safety, in which case we will need to
discuss it with you. Only the researchers will have access to information about you
and the other participants. When the project is finished, a report about the study will
be written. This report will be available for other people to read. No person involved
in the study will be named in this report.

What should I do now?

If you have any questions about this project, please ask your support worker or you

can contact Susan Collings on 02 9351 9484 or Rachel Mayes on 02 9351 9711 at the

University of Sydney. They will answer any questions you have about the project. If

you would like to participate in this project please sign the consent form.

Any person with concerns or complaints about the conduct of a research study can

contact The Manager, Human Ethics Administration, University of Sydney on + 612

8627 8176 (Telephone); + 61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au

(Email).

APPENDIX C: PARENT CONSENT FORM

THE UNIVERSITY OF SYDNEY

Australian Family & Disability Studies

Research Collaboration

Risk status and resilience in families with parents with intellectual disability project

Project team: Professor Gwynnyth Llewellyn

Ms Gabrielle Hindmarsh

Dr Rachel Mayes

Ms Susan Collings

Faculty of Health Sciences

I (name) _____

have read the information about the above named project, and had it explained to me.
I am aware that the project is being conducted by researchers at the University of
Sydney. I understand what my participation in the project will involve. I understand
that when I and/or my child are interviewed the interview will be audio-taped, if I
agree. I understand that I do not have to answer any questions that I do not want to
answer.

☐   My child (name) _____ **has given**

their verbal consent to be involved in Stage 1 of the research and I am happy for the

researcher to talk to my child.

☐   I **do not** want my child to be involved in Stage 1 of this research AND/OR my

child **does not** wish to participate in this research.

☐   I freely allow my child to take photographs as part of this project.

☐   I freely choose to participate in Stage 2 of this project. I understand this
project is not taking place until a later time.

I understand that my participation in the project and the participation of my child is voluntary, and that I/we can stop being in the project at any time if I/we wish. I understand that whether I/we take part in the project or not, the support /we are now receiving will not be affected.

I also understand that any information I/we share with the researchers will be kept confidential. I am aware that I can contact the Manager, Human Ethics Administration, University of Sydney on + 612 8627 8176 (Telephone); + 61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au if I have any complaints at any time.

_____   _____

Signature of research participant/ parent   Date

_____   _____

Signature of witness   name/designation of witness

APPENDIX D: CONSENT FORM QUESTIONNAIRE

Risk status and resilience in families with parents with intellectual disability project

Project team: Professor Gwynnyth Llewellyn

                    Ms Gabrielle Hindmarsh

                    Dr Rachel Mayes

                    Ms Susan Collings

Circle the correct answer

1.   The research is about understanding your experiences and your child's experiences of daily family life.

<div align="center">TRUE or FALSE</div>

2.   Once you join the project you cannot leave until the project is finished.

<div align="center">TRUE or FALSE</div>

3.   You have to participate in this research project.

<div align="center">TRUE or FALSE</div>

4.   Your child has to participate in this research project.

<div align="center">TRUE or FALSE</div>

5.   Participating in the project will not affect any services you are receiving.

<div align="center">TRUE or FALSE</div>

6.   Personal information about you can be shared with people outside the research team.

<div align="center">TRUE or FALSE</div>

7.   You and your child have to answer every question that we ask you.

<div align="center">TRUE or FALSE</div>

8.   By signing the consent form, you give the researchers permission to conduct an interview with you and an interview with your child.

TRUE or FALSE

APPENDIX E: CHILD INFORMATION SHEET

Risk status and resilience in families with parents with intellectual disability project

Project team: Professor Gwynnyth Llewellyn

                     Ms Gabrielle Hindmarsh

                     Dr Rachel Mayes

                     Ms Susan Collings

You are invited to take part in a research project.

Susan Collings works at the University of Sydney. She is a researcher, which means that she likes to find out about people and how they are going. If you agree to, Susan will talk to you and get you to do some fun activities, like taking photos, doing drawings, playing your favourite song. This will help Susan find out more about you and your family and friends and the things that are important to you. She wants to find out these things so she can understand what children think about their families, schools, and friends, where they live, what they like and don't like and who helps them most.

If you are happy to help her, she will meet you and your parents and give you a disposable camera so you can take photos of things and people that are important to you. After you've finished taking photos, Susan will get them developed and then make a time with you and your parents to give you your photos and talk about them.

This can be at home or somewhere else and will take about an hour. If you want, someone can stay with you the whole time. Susan will ask you if it's okay to tape-record your conversation, but won't do it unless you say that's okay.

You do not have to be part of this research project if you don't want to. No one will be upset with you if you say no. If you talk to Susan, you don't have to answer any of her questions and you don't have to take photos if you don't want to. You can also tell her to stop and she will stop straight away. Susan will not tell anyone else about what you say, unless you tell her something that makes her worry that you are not safe. Then she will need to talk to your family or your case worker about it.

When Susan has finished talking to all the children who are helping her she will write a report. In this report she will make up a pretend name for you (or you can make one up) so no one will know she's talking about you. If you have any questions for Susan you, or your parent or your family case worker can phone her at the University on: 9351 9484. She will answer any questions you have. Would you like to help Susan with her research?

APPENDIX F: RECRUITMENT FLYER

Risk status and resilience in families with parents with intellectual disability project

Project team: Professor Gwynnyth Llewellyn

                         Ms Gabrielle Hindmarsh

                         Dr Rachel Mayes

                         Ms Susan Collings

Study Alert!

Do you know a child whose parent has a learning difficulty?

Healthy Start is an initiative to support parents with learning difficulties and their children. Healthy Start is conducting research about the lives of children whose parents have a learning difficulty, focusing on primary school aged children without a learning difficulty.

A researcher from the University of Sydney will talk to children about family life, their experiences at school, such as friendship and bullying, and community participation to understand what influences social inclusion and helps build resilience. Children will take part in open-ended interviews using photography to share aspects of their lives and the people and places which are significant to them

Participation in the study is entirely voluntary. Written parental consent and child assent is required. Children will not be contacted directly about the study and no interviews will be held at school. Interviews will take place at a location chosen by the

family. This may include home or the office of a familiar family support service or social club. Interviews are likely to be one hour duration.

Transport assistance will be available. Children will be given regular rest breaks and refreshments during interviews. Each child will have their own photographs presented in a bound album printed with identifying captions as a gift.

How can I help?

If you know a parent with a learning difficulty who has a child at primary school and you think they may be interested in taking part, please contact Susan Collings on 02 93519484 or 0448294307 or at susan.collings@sydney.edu.au for more information. **Ethics approval has been obtained from the University of Sydney to conduct this study (Ref no 11006).**

APPENDIX G: STUDY 1 INTERVIEW GUIDE

THE UNIVERSITY OF SYDNEY

Risk status and resilience in families with parents with intellectual disability project

Project team: Professor Gwynnyth Llewellyn

                  Ms Gabrielle Hindmarsh

                  Dr Rachel Mayes

                  Ms Susan Collings

The following provides a broad outline of interview topics to be covered with child

participants in study 1. Topics are derived from emergent themes within child

resilience literature, and literature on families headed by parents with ID (Llewellyn,

McConnell, Grace-Dunn, & Dibden, 1999)[10].

Interviews will include the use of age-appropriate activities, such as photography,

drawing and music. Interview processes are guided by guidelines set out by the NSW

Commission for Children & Young People (2005).

1. Me and my family

    - About me – what I'm good at

---

[10] Llewellyn, G., McConnell, D., Grace-Dunn, R., & Dibden, M. (1999). *Parents with Intellectual Disability and Older Children: Strategies for Support Workers*. Melbourne: Disability Services Division, Victoria Government Department of Human Services.

NSW Commission for Children & Young People. (2005). *Participation: Count me in! Involving children and young people in research*. Sydney: Crown in the right of the State of New South Wales and Social Justice and Social Change Research Centre.

- About my mum and dad

- About my brothers/sisters

2. My role in my family

   - Special tasks that child takes responsibility for

   - What is special about the family

3. Who helps me

   - Other people who are important in child's life

   - Who helps with various tasks: e.g. homework, getting to/from school or other activities, hobbies

   - Who to turn to if there's a problem

4. School

   - Good things/ not so good things about school

   - Bullying/ teasing

5. Friends

   - About my friends

   - What we like to do together

   - What's good/ not so good about my friends

6. Where I live

   - Thoughts about where family lives

   - What's good/not so good about neighbourhood/community

APPENDIX H: FAMILY PROFILES AND INDIVIDUAL NARRATIVES

11.7. **Damien**

Family profile

Damien[11] lives in a small country town with his mother, Sally. He was about to turn 11 and start the final year of primary school when we met. Sally worked 4 days a week at a woodchip mill where she stacked pallets. The business was operated by the disability service provider which recruited Damien to the study. The formal service also provided Sally with housing and daily visits by paid workers, called "carers" by Damien, to assist with domestic tasks such as meal preparation, shopping and cleaning. According to the service coordinator, Sally had been a service client before Damien's birth and staff at the disability service took a keen interest in the family's wellbeing. For example, the coordinator reported that Damien and Sally had been guests at her own and other staff members' homes and were included in events organised for significant holidays such as Christmas and Easter.

Daily visits from the paid carers, all but one of whom was female, were an integral part of Damien's life and he could describe their daily roster. He had known some of these carers for several years. Damien explained that carers came in the morning to help him and his mother get ready and then drive him to school and Sally to work. Several afternoons a week were spent in their company. A young woman took Damien with her to walk her dogs, another took him fishing, and a third kicked a ball with him. Paid carers also helped Damien with homework. Damien and his mother took vacations with staff and other clients of the service and had recently returned from a

---

[11] Pseudonyms replace the names of all people, organisations and places referred to.

cruise organised by the disability service prior to the second interview. A school friend's mother had begun work as a carer, which meant that Damien got to spend time with his friend when his mother worked with Damien's family.

Damien's surviving extended family consisted of two uncles who lived in another town and whom he rarely saw. Damien's grandparents had passed away, most recently his grandmother, and he had never met his father. Sally had a boyfriend with whom she worked and he visited at weekends to mow the lawn. He and Damien shared an interest in PlayStation[12] and the two played games together but the three of them did not go out socially. He and his mother moved house between the interviews and visits from his mother's boyfriend ceased and Damien rarely saw him. Damien had three best friends with whom he also regularly spent time away from school. His closest best friend had moved interstate 6 months before we met. Damien had played soccer for 5 years. Two afternoons a week, Damien went to after-school care at another primary school where he took part in ball games, gymnastics and tennis.

Context of interviews

Damien and I met first in January 2011 in a meeting room at the disability service which employed his mother and provided home-based support services. I met Sally, a family caseworker and service co-ordinator before Damien and I were left alone for the interview. Damien appeared comfortable in the setting and later explained that he had spent a great deal of time at the office. After the interview he pointed himself out among the client photographs on the walls. We started off our interview by looking at Damien's photos but, as the film had been over-exposed, only five photos of a fishing

---

[12] Brand name of a popular console games device.

trip taken with a carer named Doug were available. Damien completed the social relationship diagram and free drawing.

Damien and I met again 10 months later. I liaised with the recruiting agency to obtain his family's contact details and then spoke to Damien and his mother and arranged to visit the following month for the second interview. I met them at their new home on the other side of the town and spent time talking to both Damien and Sally before Damien nominated a local park as the location for our interview. We drove to the park and sat at a table to talk. I initiated a conversation by asking Damien about the important people and activities, such as PlayStation, that he had talked about at the first interview. I asked what had changed over the year and we talked about moving house and him being able to make his own way home now. I learned he had a new best friend and a girlfriend whom he saw at school. He was about to finish primary school and would be going to a high school further away from home.

Narrative

Mum is (the person I am closest to). (Most of the time) me and mum just stay home but sometimes we walk down together to Coles[13] to get drinks. Mum does drive (but) my uncle is the boss at KFC[14] so he needed her car (and so) that's where it lives now. Mum is teaching me to cook (and) I can cook noodles, eggs and toast. I can only cook boiled eggs. I even make delicious homemade rissoles with mince. My father died in a crash accident before I was born. I think it was in Scotland (because) I was born there. Mum doesn't talk about it and I think she put all her photos of him in the coffin but I

---

[13] Australian supermarket chain

[14] Fast food chain

don't know for sure. I figured out when I was about 10 that I would have had twin sisters in the same class as me, which would have been annoying. Mum had twin girls when I was a baby but they didn't survive. They died because they didn't come out properly. I was born and a couple of months later they were born. She just acts like it never happened.

The carers come every day (because) mum needs help. They're not (my family) but I'm lucky (to have them). Carers come (in the morning) to help mum and they drive me to school. They come every day to see if mum needs any help or if she needs a life downtown or something like that and they help (me with homework). Every single Monday after school Doug takes me fishing because I got a fishing rod for Christmas. If it's pouring rain we go to the library and play on the computer. I'm one of Doug's clients but I trust Doug and I'd tell him or mum if I was in trouble.

I have two uncles (but they live) somewhere else. Sometimes we go to them at Easter or Christmas (but) they don't come here. Mum's parents are both dead now. I never met (her dad but) I was pretty sad when nana died and mum cried, too. It was a while ago. On Wednesday mum's going to sell nana's house (and) get lots of money for it. We are moving and (our) new house (is) on the other side of town so it's closer to school. I just need to survive one year (being that close) and when I start high school I'll be real far away from school again.

Mum works at (a place) that cuts up pine and she stacks the logs. (They) also do recycling and she sometimes does that, too. Last year mum and I went on a cruise (with) the carers and everyone (from her work). It was a big boat with about 12 storeys. There were (other kids) on the cruise (but I was the only one in our group). I'm not really (disappointed to be) the only child because (I get special treatment).

Every school holidays mum and I go to (the head office) on Wednesdays to have lunch and I am always allowed to play the computer. Jason is (Mum's boyfriend) and she sees him at work. (I call him) my stepdad and they've been together (since I was) probably eight. He comes every weekend to mow the lawn or something and sometimes I help him out with the PlayStation because I gave him my old one. We don't go out with him and he (has) never lived with us because he lives with this adult who has problems so he's taking care of him. Sometimes when I play my PlayStation games mum comes in. She only watches because she only wants to watch.

My school is all wrapped up with mad scooters. Whoever has the best scooter is popular (but) I don't like scooters. The popular kids are mean (and) all the year sixers last year were bullies. They were picking on the kindy kids at lunchtime when the teachers turn their back. The kindy kids run away and then the bullies chase them and push them. Me and my friends just sit down (so) they leave us alone but I'd tell the teacher (if they) hurt me (and) mum would go to the principal. I get along better with boys (and) I don't know the girls. All the girls have fights all the time and they "fake sick" so they can go home. Like this one girl goes to the sick bay nearly every day because she's hurt her foot or arm.

After school on Tuesdays and Thursdays I go to aftercare at Town Primary and we do gymnastics and go to the tennis court and kick the soccer ball around. (Another) carer (called) Amelia picks me up from aftercare but now she's getting married so she's leaving (and) I won't see her for a while. Celia sometimes takes me to her house and we walk her dogs. On Thursdays I have soccer training and the carers take me. I've done soccer for 6 years (but) I had a break last year because I was tired (and now) I'm going back. If the games are out of town then the coach drives me. Her daughter is at

my school (but) I don't really know her. Sometimes Leon comes and watches me (but my friends don't play).

Phillip and Alex are just my friends but Leon is my best friend (because) we get on all the time. We've been best friends since Year 2 (when) we found out we were both playing this game, World of Warcraft. It's one where there's other people playing on their computer (at the same time). We were talking about PlayStation 3 and the people next door to us had it and let me have a go. I play Assassin's Creed and so does he. Last year Leon moved to Queensland and (I miss him). Sometimes he emails and sometimes he comes down to visit. He just came back for a pool birthday party and stayed for 7 days (with his) grandparents. I saw him 3 days in a row and I got to sleep over. In the Christmas holidays Mum and I are going to go on the plane (to visit him) and I can stay there for probably 2 weeks. Leon and his mum are going (to come and get us) from the airport. Leon's mum is kind and I think she and mum went to school together. My friends are kind and I trust them. They already know mum needs help and they don't mind, they just accept it.

I bet in the future the games are probably going to be like real life and real people will actually be in the game. It's going to be cool. I played this game at Leon's once and I want to get it for Christmas. In the game you go through these quests and you challenge yourself to get better at them. It's like after a nuclear bomb hit the world and everything is like blown up. When you start the game you're just born and you get to choose if you're a boy or a girl and what your name is. You have a mum but no dad. When you're a baby you get to walk around in your little station called the Vault 101. There's a cot and you get to mess up and then you grow up and go to class and all that. Then you have a birthday party and you get any gun you want. Once you're

20 you go out of the vault in (to) the real world. There are raiders that eat your flesh so you need sledgehammers to shoot them.

This is a pretty good place to live. Mum thought it was a kind little town (so she moved here). It's cold in winter but I've never seen snow. They have a big pool where we used to have a diving board but then someone nearly broke (their neck) so they gave it (away). There's a skate park, there's the pool, there's gym fun (where you do) gymnastics. Some people here are nice and some aren't. Sometimes there's robberies but in my time living here I've never heard that anybody died. Like, on the news or something.

Leon came down to visit again and he even came to school for one day. It was nice (to see him). He hasn't changed, except he now has long hair down and he calls it his "wings". He tries to fly but he can't! I've got a new best friend now called Max. My friends like coming over (to) my house because mum is always happy and we can stay up late. Dylan is coming this Saturday for a sleepover. I don't know what we'll do. Probably watch movies, because my PlayStation blew up. I had it for 5 years (so) it was old. Mum said "that's it you're getting the newest edition now". It was $500 and we've got $200 left to pay so we're nearly there. Mum just wants me to know where I am so if I'm playing a game she won't have to worry about me. I'm a video "gamer" because I'm stuck on games.

Now I need a key because I'm the first one home. I wait for mum (and) the carers don't (pick me up from school anymore). (My friend) Scott's mum (is a carer now) and she comes on Tuesdays and Wednesdays and she takes me down to her house and we just play. Normally on Thursdays now Emma comes and we go down to the bull paddock and kick around the soccer ball. On Fridays mum and I go shopping with

Jane and I normally I have half a pizza for dinner. Jason (and mum) are still together (but he) hardly does (come around now) because we have a mower ourselves and people from the council come around and do (the lawn). Now he's got a PlayStation 3 and I'm getting one for Christmas so I might borrow two racing games from him. I got a girlfriend in school (called) Kayla. About 3 months ago she asked me out (and) we just hang around at lunch. Our whole class is going to the RSL (for graduation and) mum will meet her. I don't know (but I think she'll) probably (be happy).

11.8.   **Harrison**

Family profile

Nine-year-old Harrison lives with his parents Mandy and Mitch, younger brother Jonah and two dogs in a home they own and have lived in for many years. His parents were raised in this area and his grandparents and an uncle live nearby. Harrison and Jonah enjoy playing on their trampoline and Harrison likes playing games on a wii[15] console player. Mitch is a truck driver who works long hours but is never away from home overnight. To Harrison's knowledge, Mandy has never had a job. Harrison and Mandy are fans of football team the South Sydney Rabbitohs[16]. Until recently Jonah, who has attention deficit hyperactivity disorder (ADHD) and learning difficulties, had attended the same school as Harrison. Mandy explained that they had moved Jonah to another local school because he was being bullied but Harrison also thought it was because the brothers argued. Harrison often sees Mandy's mother and brother, who

---

[15] A brand name of a popular console game device

[16] A football team in the Australian National Rugby League

live together nearby. Nanny Jan is also the "crossing lady" [17]outside Harrison's school so he sees her every morning but he sees less of his other grandmother, Nanna Marg, who lives in a retirement village in a nearby suburb.

Harrison was in Year Four at the school he had attended since Kindergarten. He found it easier to make friends with children he described as having "special needs" but was not in a special needs class himself. He saw Mandy's friends and their children regularly. To his knowledge, Mitch had no friends. Harrison had played soccer for several years but recently quit the team. He was involved in a social group for siblings of children with disability and sometimes went on school holiday outings with the group.

Context of the interviews

Harrison and I met in September in 2011 at the office of a family support service which was providing Mandy with case management. The caseworker had recruited Harrison to the study but he did not know her very well and the office was not a familiar setting. However, the room was inviting, with posters and photographs of special events for service users on the walls and children's toys used by a playgroup. During the first interview Harrison frequently wandered around the room to look at various objects. He was eager to talk about the photographs which showed him at home with immediate and extended family and pets and this led to stories about his family. I noticed he was very talkative and wondered if he was nervous so I suggested we make his photo album together. Initially I encouraged him to talk about whatever

---

[17] Colloquial term used in Australia for a volunteer who assists children to cross the road safely outside their school.

he liked rather than initiating a discussion from the interview guide. For 15 minutes he told jokes and described his favourite cartoon character Ben 10, and then I was able to engage him discussions based around the interview guide. Harrison completed a social relationship drawing activity and did free drawing.

I met Harrison again 2 months later when we arranged that Mandy would drop him at the library where I had booked a meeting room. Harrison was distracted by visits from his younger brother and the goings-on outside the room and spent much of the interview playing with a soft toy he had brought along. He had made two new friends at school and told me that he and one friend played games with their teddies. The interview was cut short when the library closed so Harrison invited me to visit him at home. Mandy and I arranged that I would visit 2 weeks later in December 2011. In the 2 weeks between these meetings one of Harrison's new friendships had ended and he had also been diagnosed with Asperger's Disorder. He asked his mother to show me the psychologist's report. Harrison and I went to the lounge room for the interview but Mandy wanted to talk about her health issues and Jonah was distracting so Harrison suggested we go to his bedroom, saying, "Can we play a game now?" and then asking Mandy, "Could I play the wii with her?" As he was playing a wrestling game he talked about his favourite wrestlers and this became a focus of his stories. When it was clear that Harrison was more interested in his game I asked if he would like to end the interview, to which he said yes.

Narrative

Mum is kind, cuddly and nice. I'm closest to mum and she still calls me "the baby". Mum's got a lot of friends and (their children and) even grandchildren visit sometimes. Last weekend Jonah went to a party. Mum took him so I went to the park

and to church with mum's friend, Serena. She's got a child called Aaron and he likes me. All the parents are mum's friends and sometimes (we visit their houses). I've played soccer probably since it started except for this month. Mum got sucked into being the main soccer coach because the coach left and she'd been a coach before. One of the parents harassed her and said he doesn't want her to be coach. George is the coach (instead now) and (so) I stopped going. When someone's mean to mum it hurts her feelings. I cuddle her to try to calm her down. My mum got chosen this year for a part on the school P and C[18] to buys things for the Fathers' Day stall. She likes to do those things to help. Today I was late for (the class) excursion so mum drove me there and waited in the car for me. Basically mum and dad help me but mum's the one I'm closest to. Mum, mum, mum.

Dad and I both like jokes. He is funny and he gets jokes off the radio because he's a truck driver. We make up our own jokes too like we (make up) funny car number plates and dad can make up stories to tell us before bed. He works for Big Trucking (and) earns money. Dad is hard working and kind but he doesn't really have mates. We got to ride home in his truck one time and we didn't have to wear seatbelts because it was at night. He leaves for work at 4 o'clock and he is usually home by 6.30pm but one night he didn't come home so we drove to his work but he wasn't there. He was leaving the other way when we were getting there.

Mum used to go to the same school as I do and Nana Jan is still our school's "crossing lady". Something's going on between mum and Nana Jan (and) I'm not sure why but

---

[18] In government-funded primary schools within the Australian state of New South Wales, school-based parent organisations are governed by the P&C Federation. See http://www.pandc.org.au/

they're not talking to each other. I still see her every day at school (but she doesn't) visit now. Uncle Ian is cuddly too and he lives with Nana Jan. I used to see my cousin Kayla but we don't see her anymore because she moved to Melbourne with her mum. Dad's mum, Nanny Marg lives (near us too). Dad's brothers are Paul and Daniel. If mum goes out somewhere she'll ask Nanny Marg to mind Jonah but Nanny Marg is mean sometimes. She can go up to Newcastle and look after (Uncle Paul's) kids for a week for but she won't look after us. We don't ever sleep at Nana Jan's place. We never have and never will because I miss mum. I get nightmares every night about death and I usually sleepwalk. I call out for mum and she just comes in. On Sunday night I was sound asleep and I woke up screaming "mummy, mummy" because in my dream we went to visit my mum's grandma who mum didn't even get to see in real life because she died before she was born. Auntie Emma said she must have been visiting me in the dream but that can't be right because I was sound asleep.

Playing wrestling on the wii is basically what I do all the time and when I play I like to knock the referee out because he's a scaredy cat. Hopefully I will do it (in the school holidays). I love watching wrestling and John Sena is my favourite wrestler but none of the kids (at school) watch wrestling so I just talk to them about it. I like our backyard because I get to run around and play football with Jonah and with Luke (who is) a friend. Jonah and I like to do handstands in the pool. Dad won't let me go in a football team until I'm 18 because he doesn't want me to break my back or something. Dad's not really into football (and nor is) Jonah. Jonah will go "Go Rabbits!" and then the next game "Boo Rabbits! Go Tigers". He follows the Rabbits but he's got special needs because he's got a disability so it's hard for him to make up which team he goes for. Me and mum are Rabbitohs fans and we watch games on TV together. Sometimes we go to see games at the Stadium.

I'm placid and shy but I'm a good dancer. I don't do it in front of a crowd, though. I talk in silly ways just sometimes and I get bored easily. When other people do things I don't like I get really angry and stressed. I get out of control and all that. If I ask people to do something I don't get angry. If I could change anything I'd change people so they don't do things when I don't ask them to and then I won't get stressed. I've got a disability (called) Asperger's.

At school I play with younger kids. I like playing with kids from the special needs class and my best friend from the special needs kids is Rory. My teacher Mr M is funny but I don't like our new principal. Our old principal would come out and say "hi" every morning but he doesn't and he shouts at everyone. Once he came into our class and people got in trouble. Mum put me into a "sibs' group" because Jonah's got special needs and it's for kids who've got brothers or sisters with disabilities. It's just so you can have a break and get away from Jonah. They are going to Wisemans Ferry in the holidays but there are no spots for me (so I can't go). Sometimes at home I get a bit angry with Jonah and go to punch him when he teases me at the dinner table. Dad says "Just let it go" and I stand there and then I go back to my chair. I just need to calm down that bit and so I go to my room sometimes. Mum and dad get angry with me when Jonah and I fight which I sometimes (think is unfair). Jonah changed schools because we didn't get along and he's happier there. We also know Tyler can't pick on him now. I don't like Tyler even though his mum is mum's friend and he's got a cerebral palsy. He does things to Jonah and picked on him at school. He says to Jonah: "control yourself" and it makes me upset and angry when he does that because he's got a disability, too (so) he should know Jonah (can't do that). Well there are bullies (at school) but I don't get bullied.

I've got two best friends at school (now), Toby and Bryan, and I play games with them. Once we were playing the Kingdom of Hearts and I wanted to be Ben 10 and Bryan said "you can't play". He's done that a couple of times because he doesn't like Ben 10, and I said "fine, I won't play" and walked off and Toby came with me. Only a couple of the kids like Ben 10 but I don't mind. I wish I was Ben 10 so I could turn into one of the aliens. I don't like Bryan that much anymore because he can be a bully at times. He punched me in the stomach I (and) I didn't want to play with him (after that). Yet he got a yearly award for being good and I don't get an award much. I haven't even got a bronze one yet (which makes me) sad. At lunchtime Toby and I pretend our teddies are alive. They keep me company and teddies like kisses and hugs too. Toby's a nice boy but he's busy in the Christmas holidays (so I won't see him). Toby doesn't watch (wresting) and none of the (kids at school) like wrestling (so) I just talk to them about it. I like the moves that they do (and) I like knocking the refs out because it's fun.

Mia and Rosie's family profile

Rosie and Mia are identical twins who have always lived in a public housing flat in the suburbs of a large city with their mother, Veronica. Recently, Veronica applied for relocation by the NSW Department of Housing.[19] Although Veronica has never worked, Rosie understands that she plans to find a job when they move. The twins had no contact with their father. Rosie said she had no father and Mia said she had forgotten his name, suggesting he played no role in their lives. Apart from Veronica, the twins' other closest relationship was with their godmother, Marjorie. Although she

---

[19] Government department which funds and manages public housing. Visit www.housing.nsw.gov.au.

did not live with them, Marjorie was involved in their everyday life to such an extent that she was part of their immediate family and the girls both referred to her as "Mama". Mia and Rosie spent regular weekends at Marjorie's home and their mother and the twins took family holidays with her. Rosie and Mia both mentioned that they had a second godmother, Nancy, whom they saw less often but who drove them to appointments if Marjorie was away, as Veronica did not drive.

Rosie and Mia had a large extended family on their mother's side. Both girls mentioned their mother's sisters, some of whom they were aware were her foster siblings. Marjorie explained that she and Nancy had been respite/foster carers to Veronica throughout her childhood. Veronica had no contact with her birth parents and Mia stated that she had "got a new mum and dad" when she was a child. However, Veronica had not maintained contact with any other foster parents, apart from Marjorie and Nancy. Of her siblings, Veronica had the most frequent contact with one of her foster sisters, Michelle[20], and one of her birth sisters, Trudy. Rosie and Mia sometimes went to church with Michelle and her family. They talked about going to her home and playing with their three young cousins. Veronica's birth sister Trudy also had three young daughters. Rosie and Mia mentioned that their cousins had recently moved.

Rosie and Mia were in Year 1 at a local primary school. Each day, Veronica took them on the short walk from home to school and back. Both girls explained that, after being in the same class in Kindergarten, Veronica requested that they be put in separate classes to minimise confusion in the classroom resulting from their physical similarity. The girls said that they were happy about this as it meant they had made

---

[20] Not related to Marjorie or Nancy.

different friends. Apart from these friends, Mia and Rosie regularly saw two other children outside of school because their two mothers were Veronica's friends. One child, a boy, walked to school with them every day and Rosie described him as being "like a brother". Poppy, the other family friend, was the same age as the twins and also went to their school. Sometimes she and her mother visited them after school and sometimes Veronica looked after Poppy for her friend. The twins had been involved in a Little Athletics[21] group since they started school and both were talented runners and hurdlers. They had other friends, an elderly couple who lived in the same block of flats, and whom they helped by taking out to do grocery shopping

11.9. **Mia**

Context of the interviews

Mia and I met for the first interview in October 2011 when she was 7 years old. Her godmother Marjorie had learned about the study from a professional contact involved in the intellectual disability field. Marjorie introduced me to the twins and their mother Veronica prior to the interview so I could explain what participation entailed, give them the disposable camera and obtain consent. We met a week later at Marjorie's home. I discovered that the girls had not been able to operate the disposable cameras and Marjorie suggested that they could show me their own photos next time we met as these were not at Marjorie's home. Mia was interviewed after Rosie and I talked to both girls in Marjorie's lounge room. Mia completed a social relationships diagram.

---

[21] A national community-based organisation in Australia which operates locally based sports clubs for primary school aged children. Visit www.littleathletics.com.au

A second interview took place 3 months later. I contacted Veronica who suggested I visit the twins at their home and we arranged a date. After spending time talking with both girls and their mother I offered them the choice of being interviewed separately or together and they chose to be interviewed separately in their bedroom. Mia had celebrated her eighth birthday and started Year 2. She had a new best friend and showed me photos of a recent interstate holiday her family had taken and some of the places near her godmother's house she liked to visit.

Narrative

We've got so many people in our family (that) we don't know how many (and) some live in different states so we don't see them (often). There's Auntie Tanya and Uncle Dan who live with my cousins. (We used to) see them more but now they live far away. There's our mummy (and) Mama and Nancy (who are) our godmothers. Mama's mum and dad – we call them nan and pop – Auntie Michelle, she's our foster auntie and her kids are our foster cousins. Auntie Michelle sometimes drives us to church (and) sometimes we go to their house we play in their cubbyhouse. Auntie Gina has Liam and Reilly but there are only five boys in our family. (I met) my dad when we were little but I forgot his name. He went back where he lived, with his dad (because) he didn't want to be with our mum.

My teacher knows I have two godmothers (and) she knows when I go to Mama's place for sleepovers (but) mostly its mummy who comes to school with us. We walk (and she takes) Marco because his mum has to go to work. We wait until the half bell rings and if our mummy comes in with us we are allowed to go down to our area. In kindy (mummy) used to do reading groups (in class). Homework is easy for us because we have some help from our preschool teacher, whose name is Felicity. We

sometimes go to her house on Saturdays or Sundays and she helps us with our work because sometimes we don't know what to do. Our mummy walks us to Felicity's house but she just watches so she knows what Felicity tells us.

(Rosie and I were) in the same class in (kindergarten) but our mummy decided that when we were in year 1 we should be in different classes so people don't get mixed up. I don't play tricks (on people and pretend to be Rosie), but my friend Poppy sometimes does. If people from Rosie's class say "Are you Rosie or Mia" (she) makes jokes and says, "It's Rosie". So many people tell our mum, "Are you having any more children?" but she keeps on saying no. (I go) most places with my sister (but) before I started school I was in hospital (to fix) my right eye. Only mummy could come and stay so Rosie had to stay with Mama and she could only come and visit. (At Mama's place) we have to share and (agree which) movie to watch first. Mummy says share too but sometimes she buys us different things. Last Christmas Mama gave us a Leapfrog[22] and we share the games but we have our own games, too. (I like to have) games that are all my own. (Once, Rosie got jealous because) my friend gave me a present and it was a blue pencil case. Rosie was crying because she didn't have one so our mummy had to buy her (a) pencil case the same (as mine).

(Rosie and I) play with different friends at school but I always play with my friend Poppy. We're not in the same class but we still play with each other and sometimes she comes to our house. When her mum doesn't pick her up we take her to our house and sometimes we visit her house. I've known Poppy since pre-school (and) she was in my class since Kindy and used to be my best friend. She became Rosie's friend

---

[22] Brand name of a portable games device

because we had a lot of fights. Now my friend at school is Georgia, who was in my class last year but I didn't play with her very much then. I see her every day at school now, and we play at lunchtime and morning tea. We used to sit together in class but my teacher moved me.

(I'm closest to) Mama and my (favourite thing is) when we go to Mama's place. We go for sleepovers at Mama's when our mum needs time out. If we go Friday we get two sleepovers (but) sometimes we only get one. After school on Friday we catch a bus to the bus stop where we do Little Athletics. After it finishes we drop our mummy off and then Mama takes us home in her car. Sometimes when Mama is away our other godmother picks us up and takes us to her house to wait for Mama. When we sleep over we sometimes have our sleeping bags (in the lounge room) but mostly we sleep in Mama's room. At Mama's, we have to water her flowers and clean the dishes and at home we just have to make our bed and clean our room. We call Mama and she tells us what we can have for our (school) lunch (order) and then we have to choose one of the things she said.

After Christmas day (our family) went on a plane to Queensland to see nan and pop. We always went swimming because there's a pool right next to the house we're living in. (One day) just when we just got in the pool Rosie was sinking in a part where we can't stand on the ground. Mama jumped in with her clothes on and her hat and even her phone, too! That's why she had to get a new phone. (Mama takes care of us so) if I was in trouble I'd tell Mama and our mummy.

Once I cried at school (because) I was tying my shoe laces and there were two boys from my class and one told the other to step on the yoghurt and it squirted out and onto me. Mrs C came to the line and saw me covered in yoghurt and asked what

happened so I told her all about it. Those boys had to go to the office with me to show the lady in the office. She cleaned me up and then I had to change clothes. The second principal came to my class and told my teacher to get the boys and she had a talk with them outside my class. They're always silly and the always laugh too much in class and my teacher gets angry sometimes.

On Fridays, I go to Little Athletics. I can do hurdles and I can run twice around the oval without stopping. Once (in a race) at Little Athletics I came first and I didn't know until Mama and Rosie told me. Last week we couldn't have Little Athletics championships because it was raining so we are doing (it) this week. It's a challenge because my sister and I want to get medals and trophies.

11.10. **Rosie**

Context of the interviews

I met Rosie in October 2011 when she was 7 years old. As with Mia, my first interview with Rosie took place at her godmother's home. This was a familiar environment and Rosie appeared relaxed but was softly spoken and appeared shy. Like Mia, Rosie did not have photos but she completed a social relationships diagram.

I met Rosie again 3 months later at her home and spent time with her family before the interview. Rosie had just celebrated her eighth birthday and was in Year 2 at school. Rosie showed me photographs including those of a visit to see her elderly nan and pop, who were her godmother's parents. I asked her about moving house, which she had mentioned at the first interview, but Rosie did not know when this would happen.

Narrative

We've got over 100 people in our family and some are even overseas. There's Mama, mummy, Mia, and Nancy. We've got 10 cousins and aunties and uncles but I don't have a dad. Mummy's sisters are Gina, Michelle and Trudy and Michelle's a foster sister (because our mum) got another mum and dad (when she was a child). Mama is our godmother and we don't see (our other godmother) Nancy so much. I love (my family) and all these people love me so they're special to me. People are always asking mummy: "Are you going to have any more (children)?" (but she says) "No, two is enough". When we were five we went to a wedding because our Auntie Tanya got married to Uncle Dan (but now) they are fighting a lot. When they fight Uncle Dan has to leave. I don't see my cousins much now (because) they moved to a farm. Sometimes when our cousins come over, they mess up our room because they are little. Sometimes they clean up for themselves and (then) we don't help them.

(Mummy) is funny. She always makes funny noises and makes us laugh and she tickles us. When we're sad we hug her and when she's sad we hug her. Mama is nice and she's funny and she forgets things (but) she knows where her house is. We help Mama cook pancakes for breakfast. Once we made dinner and it burnt me. That's why we gave up cooking dinner because we're better at cooking breakfast. We only have sleepovers at Mama's house but once we had a sleepover at Nancy's and Mama came, too. Another time we had a sleepover at our auntie's and uncle's because it was a celebration for our cousins to come back home because they got taken (into foster care).

Mummy always gets up very late so we're allowed to get our own breakfast but then we have to tell her what we have. I love my sister but we always fight because she breaks my things and I break her things back. I broke her trophy (and then) she broke

mine. (Mum) screams at us (if we fight). Our mum only has to pack our lunch one day (because) we have a lunch order on Tuesday, Wednesdays, Thursdays and Fridays. We don't have sandwiches; we always have something healthy (like) rice and rice paper rolls, sushi, pasta, spaghetti bolognaise and cupcakes for a treat. We walk to school with (mum and it's not far) before you see our school. (At) the bus stop we wait for our friend, Max (who's) like a brother to us. His mother is mummy's friend and works so (mummy) takes us all into school.

We've got a family friend who goes to our school. Her name's Poppy and she is Mia's best friend. I have lots of friends (including) Omar who always sits next to me and follows me because he thinks I'm the best friend ever. Once we were having a fight and he said, "you're the worstest friend ever" and we didn't speak for about one week. We've got a new girl in our class and I have to play with her because my teacher said I was the best at looking after people.

Some friends from last year were in my class (and I've got a) fun teacher who lets us have free play. Mia and I are both writing longer sentences and I like reading with my friends and colouring in. (On Friday) we go to Little Athletics. Mama takes us most of the time but sometimes she has to go to important meetings and overseas so then Nancy picks us up. Sometimes when no one's taking us we go on a bus. (Mia and I) are long distance runners and I always come first in the hurdles. (At the championships) me and my sister want to get a medal or a trophy. In the race this year (at school) I came second. Last year I was in first and now I'm not. Cara got two ribbons of first and I only got one second (but) the rest of the people got nothing.

We've got a lot of neighbours (because) we live in a flat but not (one) with a balcony. Our friends (who live in the same block) are called Violet and Peter and we do

shopping for them because they are old. Sometimes they need to have something to eat so we go to this place like a cafe and I have spaghetti bolognaise. The person (next) door has a dog and she puts her clothes in front of the railing and we can smell them from inside our house. We don't go to parks anymore so we have to play in our bedroom or the lounge room.

There's a person who's trying to kill our mother and take us away from our mother then we won't have anyone. At least we could stay at Mama's house. There's another person who's trying to kill our mum – a guy – and there's a woman trying to kill our mother, too. (Mum) was walking to her friend's house next door and then a man came out of the middle block. He had a spanner and turned it around and said, "I'll kill you with this spanner". We were at school but (found out when mum) told her friend on the phone and mummy was crying. Now the people who move people (are getting us another home but) we have to be near to school.

We went to pop's house (in the holidays). We went to Dreamworld and my favourite ride spins around fast. Mama said I have to go in the middle or the side (because) once I went on a dinosaur train ride which was going super-fast and I got dizzy and had to put my head down. This time I tried the outside seat and I wasn't scared. We had to go back home on our mum's birthday so we finished our holiday at a Chinese restaurant with Mama, Nancy, Max and his mum and dad.

Michael and Simon's family profile

Identical 9-year-old twins Michael and Simon live in an urban neighbourhood close to the centre of a large city with their mother Kate and older brother Vincent. The family have lived in the same public housing townhouse since Vincent was born. Kate

explained that the boys' father had moved out recently after their relationship ended and they currently had no contact with him. The local area was noisy and densely populated but their small neighbourhood was an enclave of car-free roads, paved common areas and townhouses. Kate explained that she had no paid work but volunteered at a nearby charity shop operated by her church. Vincent was in his first year of high school and an army cadet but when we met Kate expressed concern about him because he had been suspended from school for drug use. She explained that the twins and Vincent had four older siblings who had never lived with her. These children had been removed by child protection services at birth as Kate had been homeless at that time. When she became pregnant with Vincent she had secured public housing and moved into the townhouse. Neither twin could remember when they last saw their three surviving older siblings. Kate said that none of her older children or any other family members visited them.

Michael and Simon were in Year 3 at the small primary school across the road from their home when we met. Three days each week for the past 3 years Simon had also attended a specialist school for children with behavioural difficulties, located further away from home, to which he travelled by school bus. Kate reported that the twins took medication to treat ADHD and Simon had also been diagnosed with oppositional defiant disorder (ODD). Most afternoons, Michael and Simon went to a local youth drop-in centre, which both boys referred to as "the centre", to play computer games. The boys had been engaged with a charity called the Auntie and Uncles Program[23] for

---

[23] This program, now called Wesley Aunties and Uncles, is operated in NSW, Australia, by Wesley Mission, a Christian charity organisation which works with marginalised communities. For details visit the website at

some years. The program provided substitute extended family support by matching an adult volunteer with a disadvantaged child for social support. Simon had had two mentors over the past few years but currently had no mentor. Michael had seen the same mentor, Sascha, for some time and regularly spent weekends with her.

Over the course of the 12 months between my meeting Michael and Simon and their final interview their lives underwent significant changes, with a move away from the area they had grown up in to live with an old friend with whom their mother had reconnected. This household became unsustainable when the old friend's boyfriend came to stay and the twins and their mother moved to emergency housing in a motel while waiting for permanent accommodation. They started a new school about which Michael was positive, but Simon continued to have problems with teachers and peers. Michael had lost contact with his mentor, Sascha.

11.11. **Michael**

Context of interviews

Michael's mother, Kate, had heard about the study from a professional contact who worked as an advocate for people with intellectual disability. I met Michael in October 2010 when I visited his home to talk to him, his brother Simon and Kate about the boys' potential participation in the study. I obtained consent and explained how to use the cameras, then collected the cameras for development a week later. I returned the following month for the first interviews. Michael wanted to be interviewed first. Kate suggested that the courtyard at the front of their townhouse would be a private place

---

http://www.wesleymission.org.au. The program sits under Wesley Dalmar Services, the organisation's out-of-home care services branch.

for us to talk but we were frequently distracted by Simon who wanted to correct something that he had overheard Michael telling me or by the noisiness of a group of adults who had congregated on the footpath beyond the front wall. Michael was pleased to see his photos, mostly of family pets and his brother and neighbours, and we decorated an album together. After 20 minutes Michael requested that the interview end but accepted my offer of returning at a later date.

Two months later I contacted Kate to arrange to talk to Michael and Simon again. When I arrived I asked the boys to think of somewhere else we could talk and they suggested the stairs of a common courtyard area adjacent to their house. I asked whether they preferred to talk to me separately or together and the boys opted to be interviewed together. They declined an offer to complete a social relationship diagram. The three of us talked briefly then I started the interview with Michael while Simon rode around on his bike. When Simon returned for the interview Michael joined in before heading home. While we were talking outside their home, passers-by greeted the boys by name.

I asked Michael what he had been doing over the summer school holidays and he talked about his new girlfriend and a great outing with his mentor. Kate arrived to take the boys to a barbeque organised by her church to celebrate Australia Day. When I made contact with Kate again 8 months later I learned that the family had moved out of the city and now lived with a friend in a small coastal town 2 hours' drive away. I arranged to visit them the following month but when I called on the agreed day Kate informed me that they no longer lived with the friend and were staying at a motel. I picked the boys up and we decided to talk while walking along a beach. We stopped for refreshments at an outdoor café and continued the interview.

Narrative

(My life is special) because I'm living in a house and because I have so much fun. (I don't think twins are special but) if we went to China that would make me feel lucky because no one gets born as a twin there. (I'm) I'm older than Simon by a minute and he's the idiot. I have a smarter mind and I am so smart at maths. Ask me what is 12 times 13. It's 156. So easy! I only live with Vincent and Simon and my mum but sometimes my brother or my sister visit but never (another brother) because we hate him and (another brother) is dead. Vincent is a medium brother because sometimes he annoys mum.

At home I help mum by taking my clothes off and bringing them down to the washing. After school I go up to the Centre and play x-box and computers until like its dark. (I play) on my own. I like to play Nintendo, tennis and soccer. There was a boy who lived near us at number 29 who (I haven't seen) since he pushed me into a table but he has a great place which has flowers. I want to invite one of my friends to my birthday. Rick had a party just over there but it's not like a party. He didn't give anything (to invite us) he just said "come". We had a water fight and that was my base over there and they couldn't get me. I climbed up and down and it was always two on two, me and Rick, because he's the best.

I have had quite a few teachers at school because at the start of each year I switch class. Some days a teacher goes on a course but I know tomorrow I'm going to have Miss W because she told me. I know the names (of everyone in my class) because it's so small. Liam is the most popular kid in our whole school because he always brings an X-box computer game to school. We don't play together because we're not friends yet but maybe in the future (we will be). He doesn't come to our house anymore

because his mum won't let him. She came to our door once and chucked eggs at it. Mum got mad. I ask him probably every day, "do you want to be friends?" I have a best friend but he isn't in my class. It's a dog called Rover. He just lives near my school. When I feel sad and I go to the fence and whack it and I go "Here boy", he comes over. (Dogs make better friends than) probably all people because they're so friendly (but I can't talk to him) because he's just a dog.

In my class there's a boy (called) Andrew whom I hate, well, I dislike. I'd say he's the meanest kid in my whole school. Andrew thinks it's funny to bug me (but) if he keeps doing it I'll dent his windpipe. One time he punched me and he was lucky I didn't hit him back. I went like that and then I stopped myself and kept playing the game because I knew if I hit him he would probably tell the teacher. I'm waiting until he gets me into a brawl with him and then I'll run off and tell the teacher. But then he will lie. If Vincent was there (when he hit me) he would go over and kill him.

I've been in the Auntie and Uncle program for a while now. I go to my Auntie Sascha's place to sleep at weekends. Once Sascha and her boyfriend Milo and I went to the top of the Sydney Tower and I made a postcard! At Christmas I went to visit Milo's parents and we made orange juice. I actually made this t-shirt too, but I had some help. (When I see Sascha) I'm going to show her the picture of my girlfriend, Greta. I haven't met her actually because she doesn't go to my school or live near here but I love her but. She met Vincent and he says every time she hears my name she blushes. If she comes down I might get it on with her. Greta is really close to my heart.

We just came up (to Beach Town) for the weekend to visit Mary, our auntie. (Then) we (moved into) her unit with her and her son, TJ. He is Vincent's friend now. We

only brought clothes and our Nintendo (for the weekend but) when Mum said we're staying I was glad. I never (want to go back home) because it's better here. I can walk around barefoot because there are no broken bottles. When we first got kicked out Mary said, "get out and don't return" and we went to the motel for 2 days. (Mum and) our auntie made up and she said, "come back" but there were lots of people drinking and her boyfriend got out (of jail) on parole. I hate him but we had a deal that if I behave he would go to bed early. He broke that deal and (so we left). Vincent left that same day to stay with dad and it's better now because we behave for mum more. We've been at the motel 5 days now. I wanted to go back and collect my mug that I made with Sascha. I feel pretty upset about losing another thing to remember her. Sascha came (to visit me) once but that was the last time I got to see her and I don't think I'll see her again. She needs my email address.

11.12. **Simon**

Context of the interviews

I interviewed Simon first in November 2010 in the courtyard of his home. I presented his photographs which he seemed excited about. The indoor photos were poor quality but he had also taken outdoor photos of children in the neighbourhood. He arranged the photos into an album and decorated it while we talked. He requested the interview end after 15 minutes but agreed to meet me again. I met Simon again 2 months later and the interview was held across the road from his home, this time partly in the company of his brother. During the intervening time Simon had been on school holidays. He was banned from attending the drop-in centre for the entire holidays and dreaded the imminent return to school but felt relieved that he would no longer go to the special school.

Nine months elapsed between this meeting and the next, in which time Simon's family had moved to a coastal town far from the city in which he had grown up. Simon felt positive about the move despite the uncertainty related to housing, as outlined previously. He still disliked school and was currently suspended from his new school. He wanted to see more of his father, with whom their older brother now lived.

Narrative

I like (where I live and) I want to stay here (because) you get to go anywhere you want on your bicycle and I like playing stuff like the Nintendo 64 games. Liam's mum is the closest to me because she lives closest to our house but some adults are evil. In my family we have two sets of twins but I don't see the others. Actually I don't have a dad anymore since he moved out. (Now, it's just) me, mum, Michael and Vincent. No dad, no auntie, no uncle. I have a pop (but he) never (comes to visit). (It makes me feel) bad (when people mix me up with Michael). We never hang out together. (My family's special) because Vincent is in the army cadets.

(I go to) the Centre, which is just for kids, to play games. I like X Box 360 and computer games but you're only allowed to play it on your own. I'm good at playing computer games because (I've practised) so hard and I learnt (but) I can't go to the Centre for the whole holidays. I don't know what happened but I'm banned.

Nobody came to see us for Christmas this year so we (ended up) staying at home. Michael (went to) Mr and Mrs K's (and) next time he goes I go. I used to have (an "Auntie"). Jacqui was the first to leave. I don't know why, but she just didn't want to

come anymore (but) I feel okay about it. Today everyone who goes to the Op Shop[24] (is going to a barbeque). It's not at the cafe (that does) for the homeless. One time I helped (serve food) and we get food. I'm not allowed to cook (but) mum can't handle all 7 days, so if I could there'd be 3 days when she doesn't have to do it. I'd make lasagne, no, pizza. Wait, I'd make pancakes! Mum makes Cheesy Mac. You don't know Cheesy Mac? It comes in a variety of flavours.

I just hate school. I have gone to Big Road School for a couple of years and I hate that frigging hellhole and am so glad that I'm finally going to get out of there. Nobody's mean to me at school. Cal goes to (both my schools) Big Road and City Primary. We play games on the computer but there's only some websites you can go on. I go on Cool Maths Games and its fun "Vers-ing" him. He says I'm not allowed to go (to his house) but now I know where he lives and he says maybe tomorrow (he'll come to my house. Then) we're going to start playing Nintendo 64 because he doesn't know I have it. Elliot likes games too but once he pushed me over and I got blood on my hand so I pushed him over. Pretty much my best, best friend is James but I don't play with him. The most popular kid in the school is Liam. I know he's nice and everyone knows he's nice but he's only nice when people aren't looking. He is so quiet every day (so I think I could trust him).

(We moved) because we got broken into two times in a week (and lost our) plasma TV. I always wanted to live at Beach Town because there's less drugs and less people that take drugs so (it's) safer. (Mary) is our auntie, and we (stayed at) her apartment.

---

[24] Abbreviation of "opportunity shop" a term used to describe a charitable organisation which distributes donations of clothing, furniture and homewares to disadvantaged people at low or no cost.

Michael, Vincent and me shared a room with TJ and Mum had the lounge room. (When Mum) said, "Hey boys, we're staying up here, we're never going back" I said "yippee". (There were) problems (when) our mum broke the washing machine (during a fight). She went like this (and hit) the machine (because) she didn't want to hit Mary. Mary chose a stupid washing machine over a person she likes so housing[25] (sent us) to the motel (then Mary said) "come" but (her boyfriend) got out of jail and he's not meant to be there. I hate him and he hates me. He stuffed it up because he can't drink, he's on parole, so we can just call the police and he'll be in jail like that. (He threatened me and) Mum said, "Come on boys we're leaving". So, I walked all the way from my auntie's to the hotel in my pyjamas! If her boyfriend's there I don't want to go back. If he's there I don't want to know my auntie.

Mum (went to this place and said) "I don't want to live there anymore. Do you have a caseworker?" She helps with everything and gives us food vouchers and hampers. (Mum's) trying to find a house for us but the person didn't show up. (Now) our house is at the motel (and at) weekends we (can) just dive in the pool. We like it but we want to live closer to school. I got suspended for a week (because) I (said I'd) break a boy's head. That boy Dylan has just hated me from the first day and I don't know why. (He was) always calling me names and I retaliated. I can't even look at him or I'll call him something. I told (the teachers) to do something and they never did so I took it in my own hands.

---

[25] The NSW Department of Housing

(Vincent) is acting like a dad now (and he and mum) were fighting so he called up dad and said, "Hey dad I'm staying with you now until I feel like coming back". He went to get away from my mum. (I called him and said) "Mum's really pissed off you're not here". But then she was really pissed off when he was here so I'm fully glad that he's gone to stay with dad. (It's not fair for us, though, because) we've only been to dad's house once and I want to go back.

11.13. **Olivia**

Family profile

Seven-year-old Olivia lives in an outer suburb of a large city with her 5-year-old brother, Tom, and mother, Monica. Despite several moves around the area Olivia had been at the same school since she started Kindergarten, apart from a short period when they family moved to another suburb about 2 years earlier. The move was prompted when Monica secured public housing after a long wait, but 3 months later, after an unpleasant incident with a neighbour, she decided to move the family back to the previous area and into private rental. Olivia had not seen her father for several years and her mother explained that the children's father had never lived with them or been involved in their care. Olivia had a 19-year-old sister who had left home a few years earlier because she and Monica did not get along and whom Monica reported they rarely saw. Monica said she had a large family but Olivia said they only had contact with one auntie and her family. She lived some distance away and they saw her at Christmas but, according to Monica, her sister never visited them. When we first met, Olivia did not do any after-school activities. She had stopped going to Sunday

school[26] because it clashed with Monica's a door-to-door sales job but Olivia was keen to return; she had done swimming lessons in the past. Olivia wanted to see friends away from school but Monica preferred them to keep to themselves.

Olivia was in Year 2 at a local primary school and had just turned eight when we met. She was driven to and from school by her mother as it was too far away to walk. By our second meeting she was about to finish Year 2 at the same school, had a new group of friends and had started several structured after-school activities. She had not seen her auntie and was still frustrated that her mother did not allow her to see her friends away from school.

Context of the interviews

I met Olivia in January 2011 at her home. Her mother Monica and I talked about the study with a caseworker from a family support service from which Monica received case management. The first interview was held in March 2011 at the office of the formal service and, at Monica's request, the caseworker was present. It was Olivia's birthday and, although she had never been to the office, she appeared comfortable with the interview context and expressed herself with confidence. She was thrilled with her photos, mostly of her school friends, and we compiled them in a photo album which Olivia decorated. She also completed a social relationships diagram. After about 45 minutes Olivia asked how long we had been talking and, wondering if she was tired, I checked whether she would like to stop. Olivia insisted she wanted to

---

[26] An institution designed to teach people, usually children, about Christianity and held at some Christian churches in Australia

continue and only asked out of curiosity. After another 15 minutes had passed I suggested we stop and Olivia expressed disappointment the interview was over.

I spoke to Monica 10 months later to arrange a second interview and she explained that she had been suffering from serious depression when we first met but had since started taking anti-depressants and felt much better. She planned to do some vocational training the following year in preparation for employment. I visited Olivia at her new home in a suburb close to where she had been living when we first met. Monica suggested that the interview be held in the family room but Olivia was unhappy with her mother's interruptions and asked to play the wii game player. I suggested that she might prefer us to talk in the privacy of her bedroom and she relaxed when we were alone. Olivia showed me some of her belongings, including the photograph of her dressed in a costume for the dance concert her sister had attended, which prompted her to confess to missing her sister. She had had a change of friendship group and commenced several new social activities since we first met.

Narrative

There used to be five people in our family but now it's just the three of us. Mum, Tom and me. Our dad's really, really, really fat! My mum and dad broke up because my dad doesn't like us because he has a different girlfriend. I didn't like him being my dad too much because he was pretty mean. I'd like a different dad. When I was five I did dancing and we had a concert. It was special because we had to do dancing in front of lots and lots of people and my sister came. That was a long time ago and I kind of miss my big sister. I've never met my mum's dad and mum because they died. The only sister my mum gets along with is Auntie Sally and we see her and Uncle Igor, my cousins Jack and Eli. Auntie Sally lives kind of far away but we see her kind

of a lot, like on holidays and Christmas. Mum doesn't get along much with her brother because they had a fight last time. That wasn't last Christmas, it was the other one when Auntie Sally had a party and we played soccer and hide and seek.

At home Tom and me normally play wii sports, like car-race or tennis or bowling or dancing or different games. Sometimes we play dolls or families and sometimes we fight. But if he's sad I tickle Tom. He comes up to me at school because he likes my friends. I'm the biggest kid in my family so I'm the boss of my room. I'm the boss of the TV because I'm the biggest and I know what to do with the TV. So that's what I'm in charge of in the house. Mum's in charge of the TV down the stairs and the oven because of the burning. I clean my room and I kind of help with Tom. We used to get ticks on the board (for good behaviour) but we don't really do it anymore because mum forgot to get the prizes for whoever gets the most ticks. She is too tired (to read to us at night) so she kind of actually reads them in the day.

Every day my mum drops us off to school because I don't have a dad. I want mum to start doing craft in my class on Fridays and said she's going to think about it. I like school and I like doing work because work's not really boring. I am in the choir and we practise at lunchtimes. We get to go places and sing and for our concert we got to sing on the stage and it was only for the choir people. All my friends are in the same year as me and I like meeting my friends and playing with them. My best friend, Sara, is pretty popular because she's really clever at school. When friends fight and get angry at me because I don't pick them as number one (in games) it makes me feel kind of angry. My best friends don't care if I don't pick them first. One day I was playing with my friends and this girl said to me, "can I play?" and I said "no" because she's really mean to me and I don't like her. She got upset and my friends were

sticking up for me and saying it was my choice who I want to play with. She's a pretty mean girl and last year she was coming up to my friends and me and saying, "I'm not your friend" and "I'm going to tell my mum on you" and stuff like that. I felt pretty sad so I told the teacher. She got in trouble and Mrs R told her she was tired of it.

There are three other naughty kids in my class who are boys. I'm scared of Ashton. He's naughty at school and he has scissors and walks around with them and my heart beats really fast. I try to calm down and take deep breaths. Today he was being really naughty and he ran up and kept bumping us and following us. He had a scary face and we had to get Mr R to give the lists but he was busy on the phone so the lady in the office gave it to him. When we walked back Ashton was right in the office and I was scared and ran. I was trying to get back to class because he was behind us with a scary face. I feel kind of sorry for the naughty kids.

When it was my birthday my teacher Mrs V gave me a birthday card and I got to have lollies. Bella and Katie came to my house on Saturday for my birthday and I can go to Bella's house next Saturday and see what it looks like and what toys she has. My mum said I can't sleep over at Bella's because I don't actually really know her that much and Bella's mum and my mum don't talk a lot so my mum's not really comfortable with me having a sleepover.

I invited Fiona and Zena to my house because they're my friends too but they couldn't come. Zena's mum said she's not allowed but I'm not really sure why. When we were eating lunch at school I gave (an invitation) to Fiona and she gave it back to me and I gave it back to her and she dropped it. Layla stepped on it and said to Fiona, "Do you want me to rip it?" and Fiona said, "Rip it, Rip it". I was pretty sad but I didn't do anything because she'd get angry and I didn't want to make a fight. I told Mum and

she said, "did you still play with Fiona?" and I said "yeah" because she's still my friend. It made me feel sad when she ripped it but when Zena said she couldn't come, well it's her mum's choice and that's okay.

Sometimes at weekends we just stay home or we go to the park or Lollipops Playland. If we have nothing special to do we just stay home. No one visits us. Mum wants to get a job but we can't stay home by ourselves. But I hope it's not a night job because I don't want to do the cooking. It can be a lunch job. I can make sandwiches but not dinner.

I moved back here because there was somebody abusing my mummy about our rabbits. (He said) that we killed their dog but we didn't so we moved back. I like this place and there's no one that comes and annoys you. It's really quiet and people don't keep asking questions and they mind their own business. It makes me feel a little bit weird when they're asking questions. I don't really (know the neighbours but a man) gives us food sometimes, like ice-creams, but now mum doesn't want me to trust strangers because we don't know him that well.

Once we were going to stay for one night (at the beach) but we couldn't because every place cost a lot of money. I told my mum I want to go bowling but she always forgets. My mum said she'll get me into swimming lessons soon but I don't do anything at the moment. I don't go to church any more but I want to go back to Sunday school where we talk about God and play games. I had a friend there but I don't see her anymore. Mum actually said this Sunday we can actually go back to Sunday school because she doesn't do Avon anymore. But she won't get up (in time). She's a sleepyhead! (Selling) Avon (is) pretty hard work but I already met this girl and I got to stay at her place for dinner. It was chicken and it was really hot and I was going "dah, dah, dah,

dah". Actually we had to get water because it was really hot but I was being funny. If anyone wants a laugh, come to me!

Kids like me because I'm kind of kind and I like to help people. Like when people get hurt I help them up or something (like that). My friends from last year don't play with me anymore so I have four different friends now. They are Carmen and Ciara, who are twins, and Shannon and Ebony. This year I do more things now Mum picks everything that's fun. On Mondays after school I go with my mum and my brother to cooking where we just make stuff like caramel popcorn. I gave Carmen and Ciara a sheet about it and they go sometimes. On Wednesday I want to ask mum if I can go back to Zumba dancing and on Thursday I do swimming and I'm pretty good at it. Friday I go to kids' gymnastics and I like doing gym because it's fun and I like doing cooking because my friends are there.

I want to go to my friend's house but mum said she had to think about which day. I've got this friend Abigail (from school) and she just lives up the road. Abigail's mum says "hi" to my mum and she's nice. We went to her house once but mum won't let me go there again. She told me once that I could invite a friend over just for the day but then she won't let me.