Submission: Protecting Victoria’s Vulnerable Children Inquiry

28 April 2011

Submitted by: Brenda Burgen B.A., B.S.W. (Hons), PhD

I can be contacted via [redacted] or on mob [redacted]

Background

The aim of this submission is to raise some key concerns and issues I have found through my academic work and in my clinical practice with people who have intellectual disabilities. Much of my practice has involved people who are, or have been, in the Child Protection System as young people, or as parents or, often, both. In particular, my clinical experience draws upon seven years of providing intensive one-to-one human relations counselling, social skills and protective behaviours education to people with intellectual disability at significant risk of abuse, exploitation or offending. I also draw on five years of experience at a major Melbourne hospital providing intensive social work support on a pregnancy care clinic specifically for women with learning difficulties or intellectual disabilities. I have written journal articles on this clinic and on women’s access to the pregnancy counselling service (see Appendices three and four). Both articles discuss the impact and high involvement of Child Protection workers. My doctoral thesis explored at length the topic of social and emotional development in young people with mild and moderate intellectual disabilities (see Appendices one and two for relevant thesis discussion).

This submission addresses the Inquiry questions:

1.1.4 Do the current strategies need to be modified to accommodate the needs of...diverse cultural groups...?

3.3.3 Do the current services accommodate the needs of vulnerable children and families from diverse ethnic and cultural backgrounds?

People with intellectual disabilities are a diverse cultural group that has different needs. Difference has ‘important implications for how we actually assess (interpret) individual people, their situations and problems (Fook, 2002, p.70)’. I believe there is an ongoing failure to understand the different needs of people with intellectual disabilities, both as young people and as parents, and that this has resulted in much misinterpretation, much inequity and a great deal of victim-blaming.

Young people in the Child Protection system

Young people with disability in the Child Protection system and leaving care are a group particularly vulnerable to abuse and neglect but there is little research into their needs or experiences. The UK government estimates approximately one quarter of care leavers are young people with a disability (The UK National Working Group on Child Protection and Disability, 2003). This seems a significant over representation of young people with a disability. It is estimated that children with disabling conditions make up 7.6 percent of the Australian population, with 3.7 percent being children with an intellectual disability (AIHW, 2004). The lack of research into this group underscores the failure to recognise this group or attempt to understand their difference and needs.

To take the specific example of young people leaving care, they have been found to be one of the most vulnerable and disadvantaged groups in society (Wood, 2008). The literature identifies three major areas of difficulty for care leavers: many are still recovering from abuse or neglect; many have experienced frequent changes of carers, caseworkers, schools and, or, poor quality caregivers; many have inadequate formal or informal supports to assist their transition to independent living (Edwards, 2010).

The difficulty for leavers is greatly amplified for those with an intellectual disability because:

- They have less cognitive capacity to understand and resolve issues of abuse or neglect and may need support for a far longer period of time to deal with these issues.

- Their learning requirements result in people with intellectual disability having difficulties in adjusting and adapting to new people and environments. The nature of intellectual disability means that the person’s capacity to transfer information and learnt skills to different people and situations is affected, and they often require assistance to re-learn skills. Frequent changes and lack of consistency are likely to be a significant setback and have long term negative consequences for this group. The Department of Human Services’ Disability Client Services (DCS) is the other support service likely to become involved with this group of young people, and because it works on a crisis driven case management model it similarly lacks consistency in response.

- It seems even less likely that young people with disabilities in care and leaving care would have supportive family or developed the informal supports to assist successful transition to independent living. Loneliness and isolation is a major issue for children and adults with intellectual disabilities. This makes them particularly vulnerable to exploitation and poor mental health.

- The usual developmental trajectory for young people with intellectual disabilities is to continue living with parents, often accessing work certificate courses and extended education and training opportunities at least until their mid-twenties but more usually into their late-twenties. The research indicates that cognitive development for people with intellectual disability occurs at a much considerably slower rate (Zigler & Hodapp,1986). Likewise, my PhD thesis supports the view that young adults delay seeking social and emotional independence from their parents until their late-twenties (Burgen, 2008, Appendix 2). The expectation of adulthood maturity and independence from carers set at the chronological age of 18 years particularly disadvantages young people with intellectual disability who, developmentally, are developing at a much slower rate. One mother explained the dilemma to me:

> ‘Robert is three ages: his chronological age; cognitively he’s around the six to seven year old level (and emotionally) responding rather petulantly, instinctively to a situation; but this has to be combined with having 30 years of life experience (p.149 Appendix 2).

As the social worker for a pregnancy care clinic for women with intellectual disabilities and learning difficulties I was concerned to find myself working quite regularly with young women whom were still in, or barely out of the Child Protection system and in relationships with much older (20+ years) men. These inappropriate, and often exploitative relationships, seemed based on the young woman’s need to be parented, and their reliance to have someone to assist them with independent living. I consider the poor and often unhappy outcomes for these women a systemic failure.

> ‘Almost one third of women (who attended the pregnancy care clinic) had been exposed to inadequate parenting and foster-care themselves and needed extra support to learn about parenting and interacting with their babies. This latter group of women were particularly fearful of Protective Services and several found their intervention raised traumatic memories. (Burgen, 2007, p.8, Appendix 3)

Recommendations

1. Investigate and research the prevalence and experience of young people with intellectual disabilities in the Child Protection system to inform policy development.

2. Develop comprehensive policies and practices that address the different needs of children and young people with an intellectual disability that will prevent a life time of abuse and exploitation.

3. Build flexibility across the child protection, disability, family services and education systems so that young people with intellectual disability can to stay in care or receive extra support until their mid-twenties.

4. Educate foster carers, case managers and child protection workers to understand and support the different rate of cognitive, social and emotional development in young people with intellectual disabilities.

5. Ensure that in planning for the future, support to develop friendships and social networks and support to develop the practical skills needed to transition as independent adults into the community are prioritised from an early age.

Parents with Intellectual Disabilities in the Child Protection system

There is a growing body of literature that indicates for a person with an intellectual disability, becoming a parent leads to systemic discrimination and high incidence of child removal (Booth, 2003; Swain, et al., 2002; Llewellyn, McConnell, & Ferranto, 2003). It is argued that the needs of parents with intellectual disability are not understood or met by the service system because neither generic parenting services nor disability specific services are willing to work with them (Spencer & Llewellyn, 2007). It is claimed that the opportunities for people with intellectual disability to parent their children are limited by prejudice and unequal access to resources, especially to appropriate services and professional support (IASSID SIRG, 2008). Much of the research concludes with the failure of services to respond adequately to parents with intellectual disability and the failure of professionals to understand the capacity of parents with intellectual disability to carry out parenting tasks (Mayes et al., 2006; McConnell & Llewellyn, 2002; Llewellyn, McConnell & Bye, 1998).

While I support the prevailing view in the literature which is summarised above, as a social work practitioner who worked directly with pregnant and new mothers with intellectual disabilities I find this view somewhat limited. The capacity to parent was not always the issue of concern or the greatest concern when considering a child’s safety and wellbeing and the involvement of Child Protection. The issue was often finding the parent with intellectual disability had a range of long-term issues such as inadequate level of basic living skills, unstable housing, lack of informal and formal supports and family violence. This prevalence of neglect in adults with intellectual disability and learning difficulty should have been dealt with by DCS or other services long before it was flagged as a crisis requiring Child Protection intervention because of a child’s involvement, (or, alternatively end up in the criminal justice system where people with intellectual disability are also over-represented). It seemed that neglect of adults with intellectual disability often becomes a Child Protection issue by default.

Dealing with the neglect of parents with intellectual disability in many cases would prevent the need for Child Protection intervention. It seemed, however, that parents were presenting at the pregnancy care clinic with the same unaddressed issues that led to previous removals. These issues often could have been addressed with long-term appropriate skills training and support following previous interventions and before another pregnancy. There was also a major issue with the way that Child Protection interventions and reasons for removals are communicated to this group of parents. The confusion that the failure to communicate in terms that are meaningful and understandable to the parents is exemplified by the pregnant mothers who told me that they would ‘keep having babies until they (Child Protection) let me keep one'. More often, though, removals were viewed as personally motivated by the workers and due to discrimination.

A key finding of my research on access to pregnancy counselling for women with disabilities was that being pregnant and having children may be one of the few times that these women come into contact with the service system and have their need for services and support recognised or reach crisis point, or both (Burgen, 2010. Appendix 4). In this study, Child Protection was involved with five of eight women who had children. The children of three women had been removed and another two women indicated their children were being cared for by family members. This supports concerns in the literature over the high level of child protection interventions that parents with cognitive impairments receive. It was problematic that Child Protection was the main source of support for these women. Apart from any other consideration, it is important to avoid ambiguous situations for the Child Protection workers, and also for the women who may have difficulty in fully understanding the workers' role and responsibilities. For example, in my study one woman believed her worker had a vested interest in stopping her from having another baby, which impacted on her pregnancy decision-making (Burgen, 2010, p.28. Appendix 4)'.

There are many other important issues that I can only touch on in this brief submission. I have seen examples of systemic unfairness such as using early parenting centre residential admissions as the pathway to assessing whether parents with intellectual disabilities should keep their babies. This is unfair because we know that due to their different learning requirements they need to be assessed in their own environments. The affected women don't easily learn or respond to intensive learning under such scrutiny or with unfamiliar people who may not understand their communication difficulties. For similar learning and cognitive reasons, expecting parents who have had their child removed to interact comfortably and well in visits with their unfamiliar child, often in the unfamiliar DHS environment, under scrutiny, without support is setting them up for failure. One of the worst professional meetings I ever attended was organised by a Child Protection team for a pregnant mother I was working with. The Child Protection workers and foster parent berated this woman for being uncaring and neglectful because she had not used the communication book they had set up. The mother was too depressed (several months later she made a suicide attempt) and intimidated to argue back that she could not read or write. The harangue did not stop until I stepped in and queried whether she could use a book. This is a small example of the ignorant response and discrimination this group receives.

Recommendations

1. Research the prevalence, issues and interventions with parents with intellectual disabilities in the Child Protection system.

2. Research the prevalence of adults with intellectual disabilities living in the community and evaluate their health and welfare status, including access to formal services and informal supports.

3. Develop comprehensive, proactive policy and practices that work across Child Protection, Disability Client Services and Family Services to address the different learning and support needs of parents with intellectual disability and work towards prevention of re-entry into the Child Protection system.

4. Require that all staff receive professional training to understand and work appropriately with parents with intellectual disabilities. Organisations such as the Victorian Parenting Research Centre have developed excellent training packages. Stronger links could be developed with the ‘Healthy Start Network’ professionals working with parents with intellectual disabilities

5. Consider developing specially trained teams with an education / training component to work across the Child Protection, disability and parenting sectors.

References

Australian Institute of Health and Welfare, Children with Disabilities in Australia, Canberra, 2004

Booth, T. (2003) Parents with learning difficulties and the stolen generation, *Journal of Learning Disabilities, 7 (3),* 203-209.

Burgen, B. (2008) *The Friendships and Shifting Emotional Investments of Young Adults with Mild to Moderate Intellectual Disability*. Submitted PhD 2008, La Trobe University. Unpublished

Burgen, B. (2007) Still not accepted: When women with intellectual disabilities choose to become mothers. *Women against Violence. An Australian Feminist Journal. Special Issue on women's fertility issues*.

Burgen, B. (in press) Women with cognitive impairment and unplanned or unwanted pregnancy: A two year audit of women contacting the Pregnancy Advisory Service. *Australian Social Work*

Edwards, R. (2010). Young people with disability. *Leaving Care*, Retrieved 02/07/2007, 2007, from the World Wide Web: www.apo.org.au

Fook, J. (2002). *Social work: Critical theory and practice.* Sage Publishing.

International Association for the Scientific Study of Intellectual Disabilities (IASSID) Special Interest Group (SIRG), (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.

Llewellyn, G., McConnell, D., & Ferranto, L. (2003), Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect, 26,* 235-251.

Llewellyn, G., McConnell, D., & Bye, R., (1998), Perception of service needs by parents with intellectual disability, their significant others and their service workers. *Research in Developmental Disabilities, 19(3),* p.245-260

Spencer, M., & Llewellyn G. (2007). Working things out together: a collaborative approach to supporting parents with intellectual disabilities. In *Planning and Support for People with Intellectual Disabilities. Eds. Bigby C., Fyffe, C., & Ozanne, E.* UNSW Press, Sydney

Swain,P., Goodfellow, J., Lee, J., Cameron, N., & Bennett, W. (2002). Pride and prejudice: A snapshot of parents with disabilities experience of the child protection system in Victoria. *Final report of the Disability Parenting and the Law Project.* Disability Discrimination Legal Service, Melbourne.

Mayes, R., Llewellyn, G., & McConnell, D., (2006), Misconception: The experience of pregnancy for women with intellectual disabilities, *Scandinavian Journal of Disability Research, 8(2-3),* p.120-131

McConnell, D., & Llewellyn, G., (2002), Stereotypes, parents with intellectual disability and child protection, *Journal of Social Welfare and Family Law, 24(3),* p.297-317

National Working Group on Child Protection and Disability (2003). *It Doesn't Happen to Disabled Children: Child Protection and Disabled Children*. London.

Wood, Hon. J, Report of the Special Commission of Inquiry into Child Protection Services in NSW, NSW Government, 2008.

Zigler, E., & Hodapp, R. M. (1986). *Understanding mental retardation.* Cambridge University Press.

Chapter 1: Introduction

Background

> … The way we understand individual identity and its formation within contemporary social structures and contexts… has important implications for how we actually assess (interpret) individual people, their situations and problems (Fook, 2002, p.70).

> [Disability research has evolved so that] now, researchers focus more on disability as a dimension of human difference… as a human difference, its meaning is derived from social construction (i.e. society's response to individuals) and it is simply one dimension of human difference (Creswell, 2007, p.86).

This study is an exploration of eight young adults' identity as friends and active participants in their own social world. It sets out to describe and understand the contexts and situations that have impacted on the formation of their understanding and experience of friendship. It is concerned with how friendships as an integral aspect of human life may be different or constructed differently for the participants as people who have an intellectual disability, and with the implications of this for understanding the social situation of people with intellectual disability. The study emerged from, and was informed by, my practice experience as a human relations counsellor and social skills educator for people with an intellectual disability. Although I no longer work in this area the study has helped me to unravel and answer some of the questions and concerns that remained with me from this work with adolescents and young adults with intellectual disability.

The research began with a colleague handing me an article written by Birch (1986) about his work with adolescents and young adults with intellectual disability and their families. Birch used the metaphor of enchantment to describe the situations he encountered where, despite evidence to the contrary, some families maintained that for the young person "… nothing new can be discovered, nothing changes, and time does stand still" (Birch, 1986, p.42). It seemed to Birch that in these cases the young person was not reaching the potential their ability indicated, and they were not moving towards becoming an independent adult. My colleagues and I also found this dynamic in our counselling and education work people with intellectual disabilities. This issue was brought into sharp focus when advocating the importance of supporting the development and maintenance of our client’s friendships when families and carers could not be convinced this was an important need for their adolescent or adult child. Their view appeared to be underpinned by disbelief that the young person’s social emotional needs would develop beyond childlike, or that one day they might want, or need, to look beyond the parents for emotional connection and support. As Birch’s (1986) discussion suggested, it seemed that the environment around the person with an intellectual disability, rather than any deficit within the person, was working to preventing growth and change. To use Birch’s metaphor, it seemed to me that many of the people I worked with had also been ‘enchanted’ into an eternal childhood.

In folklore, if a mortal wished to be released from enchantment, it was thought any attempt to escape was best made at a “crossroad”, for this was where mortal and fairy worlds intersect and where the fairy powers were most weakened (Birch, 1986). Similarly, adolescence, at the crossroad of childhood and adulthood, is a time when most young people break free of childhood and develop their independence and adult identity. Yet many adults with intellectual disability remain stuck at these crossroads, as the pervasive infantalisation of people with intellectual disability demonstrates (Carson & Docherty, 2002; Reed, 1997). Overlooking the need for friends and adult relationships seems a further manifestation of the infantilising of this group. The myth that adults with intellectual disability remain childlike is pervasive and this belief has been used to rationalise away people’s rights to adult sexual expression (Carson & Docherty, 2002). Similarly, friendships are sometimes discouraged or prevented by workers and others in contact with people with an intellectual disability because of fears this might lead to sexual relationships (Carson & Docherty, 2002; McLeod, Nelson, & Associates, 2001). It seems that, for many, fears of people with intellectual disability learning about or expressing sexuality may overwhelm understanding or acceptance of their social and emotional growth and growing need for friendships. The issues around friendship and sexuality raised by Carson and Docherty (2002) and McLeod et al., (2001) confirm and accurately reflect the attitudes I found in this area as a counsellor and educator.

The following extract is taken from Fegan and Rauch’s (1993) book on sexuality education. “Narelle” was being interviewed about her experience of growing up and she highlights the difficulty people with intellectual disability can face when wanting to live as adults, including the dilemma that can arise when development conflicts with parental expectations. Narelle explained:

> I had to do everything that Mum wanted and I'm getting to the stage where I want to do what I want [34 years]…. I left home when I was twenty-nine years old. I had a lot of pressure from my parents not to leave – I wanted to get married (Fegan & Rauch, 1993, p.39).

It seems that Narelle had reached the crossroad of childhood and adulthood in her late 20's to early 30's. Narelle is slightly older than participants in this study and she clearly illustrates how the emotional shift away from parents and the desire for emotional independence seem to develop, or becomes more evident, as young adults reach their 30's. However, Narelle's reflections indicated that her parents were unprepared, assuming or expecting her to remain childlike: do as she was told, remain at home and be emotionally fulfilled by parental rather than adult relationships. Her parents may have rightly feared Narelle would be sexually exploited and hurt but it was clear from the full interview that Narelle had grown up in an environment that prevented access to knowledge and preparedness for adult relationships and sexuality. It seems that lack of knowledge and experience, rather than a cognitive impairment as such, made Narelle vulnerable to exploitation. Narelle's story is an illustration of the importance of understanding and supporting young adults developmental needs by preparing them, and those around them, for adulthood by "dis-enchanting" them from the notion they will remain forever childlike.

The confusion about what friendship is, and the lack of friendship in the lives of many adolescents and young adults with intellectual disability was evident to me through the "protective behaviours" education I frequently implemented when I was a counsellor and educator. A major difficulty I encountered in teaching protective behaviours was how to help people distinguish between a "friend" and a "friendly stranger" when often they did not have the experience of friendship, especially of a close or best friend, in order to make this distinction. I regularly found this situation further confused by teachers or workers who in our sessions described themselves as friends of the young person. As Carson and Docherty (2002) warn, the blurring of boundaries between paid worker and friend can give a dangerous impression to the person with the intellectual disability: that they are safe with any adult who appears to be helping them. I found this to be the case with many referrals for protective behaviours education initiated because the young person had been found with strangers, or got into a stranger’s car, or other risky situations. There seemed to be little support or resources in schools or other services to actively assist friendship development. This meant supporting friendship was left to parents or carers who also may not have had the resources, or believed their active support of friendship development was necessary.

My work as an educator with people with intellectual disability who had not experienced the social context of friendship led to questions about how well social development and accompanying social skills could occur without this context to facilitate growth. From a developmental psychology perspective, friendships provide the social and interactional context through which fundamental social development occurs in adolescence and young adulthood (Bukowski, Newcomb, & Hartup, 1996). I wondered if there could have been a self-fulfilling prophecy at work where adults stayed childlike in their needs because they had not been exposed to an environment that facilitated adult development. Or, were some families, and sometimes workers, correct to argue their adult child simply did not have friendship needs or potential to develop adult social needs. How much did friendships matter to people with intellectual disability? My views were drawn from my work practice with a relatively small number of people who were experiencing social problems that were perceived as significant enough to be referred for counselling or education. Therefore, my views might not be reflective of the majority of people with intellectual disability or of their environments.

I found the literature offered very little discussion on the friendships or social development of people with intellectual disability. The psychology literature rarely discussed people with intellectual disability and while the disability literature had a body of research examining “transition to adulthood” issues for people with an intellectual disability, this literature was mostly focussed on employment and independent living and other task oriented markers of adulthood. Adulthood has been traditionally discussed as “developing through love and work” since Freud (Peterson, 1989, p.415). The focus in the transition literature on independent living and finding work, with little discussion of love and friendships seems to reflect the anxieties held by many around dealing with the emotional and sexual needs of people with intellectual disability (Carson & Docherty, 2002).

Some writers in the transition to adulthood area acknowledge and argue that young people with intellectual disability's social and emotional needs are not being met. Reed (1997) for example said that "... healthcare professionals who work with this client group have prioritised the promotion of independent living skills and the treatment of challenging behaviour at the expense of their clients emotional well-being" (Reed, 1997 p.55). Simpson (1999) also challenged the focus of professionals and services on moving people into community living with less emphasis on broader development and skills acquisition. He argued that "… the capacity to live independently [is not] 'progress' if that independence is accompanied by unemployment, squalor, and lack of meaningful relations" (Simpson, 1999, p.151). This leads to the question of what constitutes "meaningful relations" to young adults with intellectual disability, which is surely best answered with the views and voices of the young adults themselves. I found very little written about the friendships and social worlds of people with intellectual disability, and little of that had been researched from the perspective of people with intellectual disability. Many studies in the intellectual disability field, even when about adults, have been researched using the parents' and carers' observations and perspectives (Knox & Hickson, 2001). Riddell (1999) found there was a lack of detailed research from the point of view of young people with disabilities as did Atkinson and Walmsley (1999) who argued that people with intellectual disability had become the "ultimate lost voices" of our society (p.203). It therefore seemed vital to use my thesis as an opportunity to capture the views and voices of young adults themselves.

How easily the voices of people with intellectual disability could be lost was brought home to me at the beginning of this study when my proposal to interview young adults about their friendships was strongly disparaged by a senior academic without a background in disability. His negativity extended to stating to the class, after I had presented my research proposal, that he did not believe I would find participants willing or interested in being interviewed and that if I did it was highly doubtful they would be able to contribute the thick, rich description needed for a qualitative analysis. A curious parallel could be drawn here between the devaluing of the capacity of people with intellectual disability to find friendship important or to give useful description of their experience and a similar devaluing of my judgement and knowledge, which had informed my proposal for this study. It was a very undermining time to have a highly experienced researcher being so negative and to cast such strong doubts on my views and to make this very public. It would have been much easier to conform to the pressure but I believe the results of this study would have been far less valuable without the view and voices of young adults with intellectual disability. It is my intention that this study will contribute towards a critical mass of research that demonstrates the feasibility as well as necessity of ‘un-silencing’ the voices of people with intellectual disabilities.

Even though I no longer work as a social skills educator and counsellor I still apply the understanding and knowledge gained through this study in a number of ways. For example, I now work in a major public hospital and am the social worker for a dedicated pregnancy care clinic for women with disability. It is important to be aware of the social developmental needs of the women with intellectual disability that attend the clinic, the majority of who are aged less than 30 years. A knowledge of their social developmental stage helps to contextualise life and relationship choices when counselling and advocating for women, as does awareness of the environmental impact of growing up with an intellectual disability in terms of access to information on sexual and reproductive health. The complex nature of many women’s social lives: the exploitation, isolation and lack of informal social supports continues to underscore for me the importance of ensuring that young people with intellectual disability learn how to develop and maintain close, supportive friendships and that this experience and skills should be in place by young adulthood.

Research Aims

According to the psychological literature, friendships are central to young people’s social development (Bukowski et al., 1996). However, the importance of friendships, or lack of them, and the impact of this on the social development of young adults with mild to moderate intellectual disability, has not been investigated in the literature. The knowledge gained in this study about young adults’ friendships will contribute towards better understanding of their friendship and social development needs, and to improving services, policies and the practice of people who work with this group. This study will also contribute towards challenging perceptions that people with intellectual disability have different friendships needs to typically developing people or that they might not experience development of adult social needs.

Friendship is a shared and social experience, and also a subjective and individual experience. Although friendship can be explored and understood from a range of objective standpoints, in this study I am primarily interested in the subjective and lived experience of young adults with mild to moderate intellectual disability. This is because the studies that have investigated people with intellectual disability's friendship experiences have often been observational and drawn on parents', carers' or workers', or the non-disabled friend's observations and perspectives. A consequence of this has been research largely driven by parents', carers' and researchers' views of what constitutes important relationships for people with intellectual disabilities. For example, the emphasis in many studies has been on friendships with non-disabled people but, when asked, people with intellectual disability have indicated their most important, reciprocal relationships have been with others with a similar disability (Cuckle & Wilson, 2002; Heslop, Mallett, Simons, & Ward, 2002; Knox & Hickson, 2001). Thus vital information and concerns from the perspective of people with intellectual disability may have been missed.

Social Development

This meaning unit reports on the different themes related to aspects of participants' social development. The first three themes relate to social emotional development and describe the different importance that younger and older participants gave to their friendships and to opposite sex friendships or relationships. These descriptions were supported by the findings of the "Eggs in a basket" exercise. This is followed by the theme of parental expectations of their child's development, explored to contextualise the encouragement and support available to participants to develop the skills needed for adult social life. The last theme presents participants' descriptions of how they viewed their disability and reflection on the literature speculation on how disability is integrated into self-identity might be a key aspect of social cognitive development.

Age Related Importance of Friendships

> [Do you ever wish you could get out and see more of your friends?] "No, my parents are around" Cathy [a younger participant who attended social activities occasionally on the weekends and one night a week]
>
> [Do you feel like you have enough friends and go out enough?] "I need more of that" Robert, shaking his head emphatically [an older participant who named a very long list of people as friends and attended activities across every weekend and at least several nights a week]

All of the participants indicated that friendships were important to them, although the participants with complex friendships described friendship as a deeper and more meaningful experience than the others. However, the importance participants gave to their friendships was related to their age and not to complexity of understanding. Lisa, Simon, Cathy, Cindy, Mandy and Jason were the six younger participants aged from 19 years to 23 years and in discussion of friends and social activities they talked about their parents, described activities with their parents and several stated they wanted to spend more time with parents. This runs counter to Evans and Poole’s (1991) study that found that typically developing young adults did not want any association with family in their leisure activity. Robert and Graham were the two older participants at 29 years of age. Robert and Graham went out with their parents and engaged in activities with their parents too, according to their parents, but Robert and Graham did not discuss this or talk about their parents like the younger participants, instead their descriptions focused on friends and activities with friends and they indicated they wanted to spend more time with friends.

Thoughts about parents came through in the younger participants’ discussion in different ways. For example, when Mandy was asked what was special about being friends with Cindy she raised the subject of mothers in her answer: “Her mum is like my 2nd mum, Karen’s mum is like my 3rd mum too… and when I’m out doing something with them they’ll say stick with me so you won’t get lost…” At another point Mandy stated “I miss them [her parents] when I go out [to recreation programs] because family does come first anyway”. Jason discussed his girlfriend in terms of their families “…Natalie and I hang around together, our mums are really close friends, it’s like a big family – like we [Jason and his mother] are part of their family”. On several occasion Cindy told me that her “…family comes first before my friends”. None of the younger participants said they would want to spend more time with friends. The following statement from Cindy encapsulated the lesser importance of friends in relation to parents for the younger participants:

> I see my friends everyday so I don’t need to see them on weekends…I’m busy cooking, cleaning on the weekends and watch TV and I pray no-one rings – I’m not being nasty I just felt like a quiet weekend…no-one rang anyway [so you just like to have a quiet time to yourself on the weekend?] hmm and my family.…I like going out on the weekends but not all the time, I’m not a going out person I like to stay at home and do my jigsaw puzzles and seeing my sister.

In strong contrast Robert focused on describing the many activities he was involved in with peers, and Graham described his peers from No Limits and then fictional best friend, girlfriend and their activities together. Neither participant referred to their parents or to wanting or being in their parents' company at all. Robert's mother who was very involved in facilitating activities and services for adults with intellectual disability indicated that she saw a general change in emphasis on friends in the 30 plus age group: "People with intellectual disability in this older age group want to make friends and often mistake friendliness for friendship and when it's not reciprocated they get hurt and, or, pursue too hard." Robert's mother highlights here what is well known anecdotally in the disability area: that the shift of emotional investments into friends and intimate relationships, and away from parents, seems to occur for people with intellectual disability from their late 20's and 30's. Discussion of this shift seems to occur only incidentally in the literature, as was discussed in "Narelle's story" in the Introduction Chapter (Fegan & Rauch, 1993). The shift in emotional investments away from parents and into friends and then intimate relationship occurs in typically developing people in their late adolescence and early 20's. To what extent the longer time people with intellectual disability might take to reach this stage is due to slower developmental process and how much might be due to unsupportive environment is not clear.

Robert was an older participant at 29years. Robert was very outgoing and friendly. Robert described himself as a comedian, talkative, and that he enjoyed socialising especially visiting people and making friends. Robert was a "big North Kangaroo [football] fan". He identified having "many friends" and produced a list from his bag of his girlfriends' names "…yes, I have eleven girlfriends and I'm still available".

It was difficult to tease out specifics from Robert: most of the time "everyone" was his friend and he enjoyed doing "everything". Teasing out why friendships mattered to Robert mostly came down to a discussion of whether the friend barracked for the "right" football team. This seemed to reflect that although there were many peers and much activity in Robert's social world there was an absence of closeness in these relationships as described by the complex thinking participants.

When asked whether he would say he had an intellectual disability Robert said "no" but that he did have trouble with his eyes sometimes, possibly a reference to physical appearance and Downs syndrome. He identified that "some people" at No Limits had intellectual disability and "some are in wheelchairs".

Robert was older than his classmates and he did not identify anyone from the class as friends. He said he had "… made some good friends [when at special school, about ten years before, but he]… now has new ones". His mother confirmed that Ian, of the two closer friends Robert identified, was someone he had known at special school and that she and Ian's mother were close friends. Robert saw Ian through ballroom dancing and a church friendship group. Robert was the most socially active participant, which was reflected by the many people he listed from the respite and recreational activities that he attended on weeknights and weekends. While he identified many peers as friends, Robert also included several workers and teachers, and at one point said his teachers from secondary school were more important to him than the current peer friendships but could not explain why he thought this. Robert did not see any friends informally except when on weekend respite which seemed to provide a lot of organised activities. Robert was reliant on his parents for transport, as he could not independently access public transport due to physical health issues.

Opposite Sex Relationships

Another significant indicator of the different emotional investments described by older participants was their ease in discussing opposite sex relationships. Both Graham and Robert initiated discussion about the opposite sex and happily indicated their interest in this area when talking about friendship. Robert showed me his list of girlfriends at the first interview and, similarly, Graham talked about his fictional girlfriend from the first interview. The younger participants in contrast seemed uncomfortable with this area, for example, Jason at first only discussed his male friends and only with prompting did Cindy and Lisa speak about their boyfriends and Mandy about an ex-boyfriend. Some confusion may have been due to language and my asking about friends at first and not specifically stating girlfriends or boyfriends however this was not a problem for Robert and Graham who both seemed to find this a far more interesting topic than the younger participants.

Cindy and Lisa did not seem particularly enthusiastic, or have much time for their boyfriends. Cindy said she was happy to see her boyfriend only about once a month at a disco. Lisa expressed caution about becoming involved too quickly with her boyfriend, reporting that “We mainly stick to a big group and we’re with people we know around us, sort of start there before we go for a more independent sort of thing”. The young women’s boyfriends did not appear to mirror or replace the emotional intimacy or support they looked for in their close same sex friends.

Jason called Natalie his girlfriend and they spent a lot of time together outside of No Limits, however his description of their time together did not seem to describe an emotionally intimate partner rather than close friend. For example, Jason described his routine of spending weekends with Natalie in terms of their mothers: “…My mum is there because I can’t drive” or Natalie visited him “…because we [Jason and his mum] don’t mind having her and it gives [Natalie’s] mum a break for a few hours”. I asked Jason if he ever wanted more private time with Natalie given they spent most of their time together in the company of his or her family. This question seemed to surprise Jason greatly and he responded: “…Well, no, she likes to catch up with my sisters and whatever and I don’t have any problem with that…”

A further point of difference between younger and older participants was that both older participants, Graham and Robert, brought up sexuality in the discussion. In Graham’s frequent discussion of his fictional girlfriend he talked about kissing her. Robert was not able to describe the eleven women he named as girlfriends and whether they were aware they were his girlfriends or if there was a difference between them and the other friends he named. However, he could tell me that he enjoyed kissing one of them, which in fairness to Robert was an easier or more “concrete” act to describe. This interest in sexuality contrasted with the younger participants, for example Jason became embarrassed and avoided eye contact when I asked what he meant when he told me he “hadn’t been doing anything” with his previous girlfriend indicating in a very roundabout way that nothing sexual had taken place. Simon blushed and stammered when I asked if he thought he might have a girlfriend one day. None of the female participants raised the subject of sexuality, apart from Lisa who incidentally indicated she felt sexually exploited by a previous partner.

In comparison with the older participants, opposite sex relationships appeared to be of far less importance or interest to the younger participants. Nonetheless the younger and more complex thinking participants Jason, Cindy, Lisa and Mandy were more actively exploring and developing relationships with the opposite sex. Their descriptions resonated with the literature that indicates young people first explore self in relation to others and learn about reputation and status through same sex friendships, with peers strongly influencing who to go out with and how to behave. These steps and the skills learnt are pre-requisite to intimate relationships (Bergevin et al., 2004; Fullerton & Ursano, 1994). The situation of the two older participants who expressed greater interest in the opposite sex and intimate relationships leads to questions about what happens when people with intellectual disability reach adult maturity in their social emotional development but have not developed the friendships and relationships or prerequisite skills to support the shift of emotional investment away from their parents and into intimate relationships.

“Eggs in a Basket”: Emotional Investments Exercise

As an alternative to exploring the importance of friends through direct discussion, I adapted the “Which basket are your eggs in?” exercise reported in the Burns and Dunlop study (2001). The exercise had been originally developed by a family therapist for use in clinical practice and had been adapted by Burns and Dunlop for their study of emotional investments in families that had experienced divorce. The exercise had been developed to illustrate the concept of emotional investment to those who might find discussion of emotional investment too abstract or theoretical, including children (Burns & Dunlop, 2001).

To introduce the exercise into the interviews we discussed this was another way to think about and discuss the people that mattered to the participant. With verbal consent to proceed, I presented each participant with four baskets and attached four labels: Mum, Dad, Self and Others. I then handed the participants12 plastic eggs. I asked the participant to reflect on how much of their time, thoughts and caring they gave to the person or people labelled on the baskets, and asked them to allocate the plastic eggs accordingly. Questions were asked either about changing the name on the basket or about which friends should be included in the “others” basket. Participants responded positively to this task and needed little if any extra explanation before proceeding to allocate the eggs. After the eggs were allocated we discussed and reflected on the exercise, for example I asked participants who they were thinking of when they placed eggs in the “others” basket. The following table sets out participants’ allocation of eggs:

Table 2. ***Participants' Distribution of Eggs, Representing their Emotional Investments***

Participant	**Mum**	**Dad**	**Self**	**Others**	**Sisters**
Stuart	3	3	4	2	
Lisa	5	0	2	4	
Mandy	3	3	3	3	
Cindy	4	4	2	Friends were discussed separately after Cindy had allocated and discussed family and prioritised her older sister over her friends	2 Cindy said she wanted her eggs for Others to be allocated to her older sister.
Cathy	4	4	3	1	
Jason	3	0 Jason had little contact with his father who lived interstate	4	2	3 Jason requested the basket for his father be changed to his sister
Graham	4	3	5	0	
Robert	3 Robert indicated his mother had been sick so this was more thought than he would usually give her	1	3	5	

The results from the “Eggs in a basket” exercise supported much of the discussion in the interviews. The exercise supported the different importance that younger and older participants placed on parents and friends as they had identified in the interviews. For example, Robert allocated more eggs to “others” than to his parents or himself, reflecting his focus on friends in the interviews and the shifting investments away from parents. The younger participants allocated more eggs to their parents, than they gave to themselves, and far fewer eggs went to “others” than to parents. Interestingly, both Cindy and Jason requested, without suggestion on my part, allocating eggs and creating baskets for sisters, this represented significant emotional investments into their sisters and supported their description of sisters as important social supports. The exercise also served to clarify the following important points:

Firstly, the reality that Graham did not have the close friends he reported in the interviews was reflected in this exercise where he allocated no eggs to the “others” basket. I think that given Graham did not discuss his parents at any of the interviews that he would have allocated fewer eggs to them and made a distribution similar to Robert if he had the friends and social life that he imagined for himself. Finally, Graham allocated the most eggs to the “self” basket of all the participants, which perhaps reflected he experienced the greatest isolation.

Lisa’s distribution of eggs to “others” was the next highest after Robert but rather than shift in investments this seemed a response to the difficult relationship she had with her father who she allocated no eggs to. After the exercise Lisa explained she gave no eggs to her father because “… He like mainly keeps to himself and doesn’t really express himself too much to the family so we sort of do the same to him”.

In the interview with her parents they both reported that when Lisa’s father did “express himself” it was usually in the form of arguments that ended with Lisa very upset. This difficult relationship may have influenced Lisa to feel more peer oriented than the other younger participants as young people can become extremely peer oriented if they feel parents are overbearing, restrictive and give few opportunities for decision-making (Mayseless et al., 1998). I did not think this indicated a shift of emotional investment like Robert demonstrated, as Lisa still gave more eggs to her mother than to “others” and she discussed her mother in the interviews as a source of support and company.

The lesser importance that younger participants placed on girlfriends and boyfriends was reflected in the exercise. For example Jason's allocation of eggs demonstrated he prioritised his emotional investments into his mother and sister. In the discussion that followed the exercise Jason reported that Tim and Joe were the people he thought of for his "other" people basket. When I asked him why he had left Natalie out of the exercise he became very embarrassed and wanted to do the exercise over again out of concern that she might somehow find out he had forgotten her. Neither Cindy nor Lisa included their boyfriends in the "Eggs in a basket" exercise. When asked afterwards they were both adamant that the boyfriends did not belong with family or friends and they did not want to include them in this exercise about the people who were important to them.

A final interesting point was that all the males, except Robert, allocated themselves more eggs than they had allocated to either parent. A greater allocation to "self" may have been an indicator of self-reflection, which is part of the later adolescent developmental stage before the shift of investments into intimate relationships (Burns & Dunlop, 2001) but their discussion did not support this and a more likely explanation is that of gender bias, with young women being more socialised to put others first.

Parental Beliefs and Expectations of Development

> Robert is three ages – his chronological age, cognitively he's around the 6 – 7 year old level [and emotionally] responding rather petulantly, instinctively to a situation but this has to be combined with having 30 years of life experience. This all impacts on his ability to make and keep friends… Robert's mother

The literature indicated that parental beliefs and expectations have an important impact on their child's development into independent, autonomous adults (Bergevin et al., 2004; Youniss & Smollar, 1985). The difficulty some parents might have in developing expectations when their child has an intellectual disability was highlighted by Birch (1986) in his discussion of "enchantment" when development is not perceived or believed possible. Heyman and Huckle's (1993) study of parents preventing exposure to everyday risk and Todd and Shearn's (1997) study of parents working to hide disability from their adult child with an intellectual disability also indicate difficulty with developing age appropriate expectations of people with intellectual disability. Robert’s mother in the quote above illustrates the struggle of trying to apply models from typical development to understand and describe the development of adults with intellectual disability. When asked, the parents of participants seemed generally unsure of what developmental expectations to have. However, discussion indicated expectations that the young women, in particular, were likely to remain childlike, this applied to a lesser extent to the males as well and it generally seemed difficult for the parents of participants to envision their child as an adult. For example Simon’s mother reported that Simon “… really only goes out with me or hubby or he just doesn’t have any interest [in social activity] really… but I was pretty much the same when I was little”.

It was striking to hear a young man of 19 years described as a “little” child. This perception conflicted with the physical and chronological reality and reflected a view that Simon was relatively unchanged from the time he was a little child. A similar perception of no change in her child was indicated by Cindy’s mother who stated she would never allow Cindy to sleep over with friends or go into respite because at the age of eight Cindy had gone to Mandy’s for a sleep over and became anxious and had to be brought home. This implied the belief that at 21 years of age her adult child would respond in exactly the same way as she did at eight years of age: that in the intervening thirteen years no development had occurred and that a new attempt was not worth making. Heyman and Huckle’s (1993) study found some parents similarly referred to incidents from many years before as reinforcing their view of everyday task and behaviour as hazardous. In effect this undermined opportunities to learn and practice the skills that support adult development and this affirms perceptions of not being able to cope with the adult world. In general, the literature reflected that many parents and services are reluctant to allow their adult child or client to explore every day adult tasks because of fears for safety (Heyman & Huckle, 1993; McLeod et al., 2001; Sykes, 2005).

Parents were asked for their thoughts on where their child would be in five to ten years such as where they might be with relationships or getting married. In most cases it seemed that parents did not believe their child would develop adult needs nor had the ability to develop necessary skills. Lisa’s parents responded they did not “… know if she could cope – depends on how she goes later on…you see the boys in No Limits they change like the wind, it’s just really nothing…” Similarly, Cindy’s mother replied “I don’t think Cindy would ever be interested in a real boyfriend / girlfriend relationship, sexual or anything like that, she just likes them as friends” and that she “… would have thought [Cindy would be] more like an eight or nine year old, I don’t think that will ever change”. Cathy’s mother responded “… young people see the partner thing on the soapies and they want that and the children but they have no idea really of what skills would be needed to sustain that sort of relationship… that’s the struggle, the hard part, trying to grow up and not really having the skills…”

The young women themselves indicated they were not, at the time of the interviews, strongly investing themselves in boyfriends. This supports parents’ observations of unreadiness or disinterest in intimate relationships, but parents’ comments indicate they thought this would not change. The young women’s reports indicated that they had many of the social skills, or social cognitive development, needed to develop intimate relationships when they were ready, although Cathy less so. It seemed that some of the parents, of the young women in particular, were unprepared for the eventual development of emotional independence in their children or for the possibility their child’s emotional investments might eventually shift to intimate relationships. However, some parents’ observations reflected that change and growth in their children, to more independent and autonomous outlooks and decision-making was taking place. For example, Simon’s mother had reported that “…he’s a bit more sociable than he used to be, liked when he was very, very young even [when he was with someone he] knew quite well like a neighbour he used to be very, very quiet but now, all of a sudden, you’ll be talking to someone, and he’ll be into it especially if it’s something to do with a topic he knows something about like transport…”

Participants’ reports indicated there was change and growing independence in their outlook. Lisa demonstrated a growing confidence and independent sense of self, for example when talking about an ex-boyfriend she commented that “… there’s a lot of people who have too much control over me and I’d like to stick to my own decisions and things like that and I don’t like people taking control of my life, making decisions for me I prefer to do things myself…” Cindy said she had not told her parents about her current boyfriend as she knew that they did not like or approve of him, she kept in contact through text messages, mutual friends and saw him at the local discos. These participants were all asserting themselves and their individuality in different ways demonstrating a subtle shift to more independent and autonomous behaviour.

Parental downplaying of expectations of their children forming adult relationships might be partly explained by fears that daughters in particular are at risk of exploitation. Jenner and

Gale (2006) found that parents and carers of females especially feared sexual exploitation and abuse. They speculated these fears were the reason that fewer women than men applied to use their supported dating, and they believed parents and carers were preventing females from attending the service due to fears of exploitation. The downplaying of the possibility of their daughters forming intimate relationships by parents raised, for me, questions of whether participants would be prepared to deal with these relationships when they occur, something already experienced negatively by Lisa. This is a classic deficit learning cycle where lack of information or misinformation leads to fewer opportunities to learn appropriate information or skills or behaviours, which leads to making mistakes, which are then often interpreted as behavioural issues or some lack in the person: blaming the individual rather than the failure of the environment to support learning and development in the first place.

Parents of the male participants seemed far less apprehensive of their sons being in relationships and their reports supported the literature finding that women with intellectual disability are often prevented from forming opposite sex relationships by parents and carers. For example, Graham's mother said she had tried to support Graham to go out with a girl from No Limits a few years before the interviews but the girl's parents told her they were afraid the relationship might become sexual and would not allow their daughter to go out, even with Graham's mother present to supervise the couple. Graham's mother said she dreamt of "… Graham being married, probably to someone like him from No Limits and that she "…would support them both if that would make Graham happy". Robert's mother also commented on barriers to forming relationships "… [Robert] has a couple of [love] interests in the dancing crowd [he attended ballroom dancing weekly] they give each other birthday presents, dance together, have a cuddle together but it's a big problem for people with intellectual disability – they're not supposed to have those feelings and don't have anywhere to pursue this…" Jason's mother indicated Jason's relationship with Natalie was not likely to progress further "…well I don't think the marriage bit will happen, as much as those two might like it Natalie's parents would never agree to it, she's their baby… her parents are too protective of her [to allow marriage] she's their baby and will always be a baby…"

Sometimes it was beyond parents' resources to support full independence and appropriate adult behaviour, as Robert's mother stated:

> [Robert] can't do it by himself [participate in the normal mainstream of life because he is a person who wants to do these things] but who's going to do it with him and he doesn't want us there – we're his parents, he's 30 years old, who wants to hang around with their parents at 30?....He can actually exist quite well without us he is quite an independent, competent young man, except that he needs assistance getting to places and doing things. He has two very real constraints: the inability to arrange to get out to places and back again for himself and having the money to do it – if he wasn't living at home he would have no spare money to go out, therefore he wants to get out [live independently] but can't.

Self-identity and Integrating Intellectual Disability

A key aspect of social cognitive development in young people is the creation of a stable and coherent sense of identity and self-concept that is their adult identity (Bergevin et al., 2004). However, developing a realistic sense of identity may be particularly difficult for young people with intellectual disability who may encounter disparity between self identity, social identity and the way significant others may construct or even keep their intellectual disability hidden from them (Shulman & Rubinroit, 1987; Todd & Shearn, 1997). The majority of participants in this study seemed to find questions about intellectual disability confusing or confronting. Only Cindy and Lisa spoke with ease and insight about their impairment. On being asked whether she would say she had an intellectual disability Cindy reported that "… Inside I have [a disability] but you can't tell by the outside, so people look at me thinking hang on she doesn't have a disability, they don't know it's on the inside. When it comes to work I'm very slow [do people understand that?] I don't know that's up to them it's the way I am". When asked whether her friend, April, had a disability Lisa replied "Yes, April has a disability, the same one as myself [what kind of disability is that?] With me it's something like a mild to moderate intellectual [disability] I mean I sort of find that in some areas of work I may be slower in than others, I'm quick thinking but with my school work slow and that…"

I was impressed by Lisa and Cindy's matter of fact attitude and confidence as they explained their disability to me. On the other hand Mandy became flustered and annoyed when asked whether the friends she named from primary school had disabilities and exclaimed "No, they're normal like I am [is that someone with a disability or not?] No!" After further prompting and later in the discussion Mandy explained she had a “hole in the heart” the same as Cindy, who had earlier explained to me that her disability was caused by trauma at birth, and that the hole was closing up. This discussion indicated Mandy had not positively integrated her impairment into her sense of self. Shulman and Rubinroit (1987) suggested that some young people might “separate” the impairment from their sense of self and while most of the time they might feel positive about themselves they would experience stress if put in a situation that forces some recognition or acknowledgement of their disability. Mandy, who was otherwise cheerful through the interview, appeared to find discussion about disability stressful so I did not pursue the matter further.

When the other participants were asked whether they would say they had an intellectual disability they either changed the subject or, if prompted, indicated they had a physical disability. Several participants acknowledged there were others in the course who had an intellectual disability “some are, some are in wheelchairs”. Robert reported he would not say he had an intellectual disability himself, but sometimes he had trouble with hands and his eyes, possibly a reference to having Down syndrome. Jason referred a number of times to his evident physical disability and continued to discuss disability in terms of this, indicating that attending the course was proof he could not have an intellectual disability. Similarly, Mandy said she was planning to continue with her course until eventually she became a dental nurse like her sister.

Jason’s response to the question of disability seemed particularly interesting given his long-term friendships with Tim and Joe who did not have disabilities. Perhaps his frustration with them over his not having a car or driving license was due to his own unclear sense of his impairment and, from this, having unrealistic expectations such as believing he really should own and drive a car the same as his friends or believing they have this expectation of him. It seemed possible that Jason had “separated”, rather than integrated, his impairment into his sense of self, as discussed by Shulman and Rubinroit (1987). In Jason’s case, contact with Tim and Joe, and the issue of driving, could be acting as an uncomfortable reminder of his impairment, which would have been a source of stress on the friendships. A more realistic sense of self, with impairment as a comfortable part of his identity, may have prevented the breakdown of Jason’s important friendships over what seemed to be a relatively minor matter.

Rapley et al., (1998) contended that most people were aware of their disability and its social significance and chose to confirm or deny this at different times. However, most of the participants in this study seemed very unsure and unclear about what intellectual disability was or found it a difficult or painful topic to discuss. Their responses came across to me as confusion and discomfort with the idea of intellectual disability rather than making choices and being in control of the discussion. Participants' responses certainly indicated they were not familiar with discussing the topic of intellectual disability, which supported Shearn and Todd's (1996) contention of disability generally being kept secret from people with intellectual disability. Cindy and Lisa who gave matter of fact explanations and conveyed the view that people could take them as they were came across to me as the only participants who were in control and comfortable with their identity.

Developing a positive concept of their impairment or disability, as an integrated aspect of self-identity would seem an important aspect of social cognitive and adult development. Shulman and Rubinroit (1987) speculated this integration would support relationships with a better internalised, abstract understanding of their self, and self in relation to others. This integration did not seem addressed for most participants. The participants who demonstrated, to me, the greatest understanding of themselves and others were Cindy and Lisa, which supports the above contention. Participants' responses in the present study suggested they would benefit from being supported and educated to build a better understanding of intellectual disability and, or, in integrating this in a positive way into their identity. This understanding would require the support of parents, teachers and other information givers around young people and adults with intellectual disability.

(Published in: Women against Violence. An Australian Feminist Journal. 19 (2007), Special Issue on women's fertility issues)

Still not accepted: When women with intellectual disabilities choose to become mothers

Abstract

For most women fertility choices centre on when and where they wish to have their babies. Although there are numerous forms of discrimination and violence associated with women, pregnancy and childrearing, becoming pregnant and raising children is generally met with social approval and support for most women. However, social disapproval and prevention of women with intellectual disabilities from becoming mothers has a long and very unpleasant history. We may argue that we no longer overtly discriminate; sterilize and segregate women with intellectual disabilities, but whether the discrimination and systemic abuse has really gone or has it just become less obvious is debatable. This paper explores some of the social and systemic issues that impact on the lives of women with intellectual disabilities during pregnancy and early motherhood. It asks why motherhood is such a fraught and unsupported choice for these women and offers some potential best practice responses.

Introduction

This paper has been written drawing upon current research on parents with intellectual disability and fifteen years of experience working with people with intellectual disability, and specifically three years of practice experience and insights gained as social worker supporting the women who have attended the Women's Individual Needs (WIN) Clinic. The WIN Clinic is a pregnancy care clinic situated within the maternity programs at the

Royal Women’s Hospital. Attending the clinic is voluntary. Information on the clinic is provided to women who either identify or present as having an intellectual disability or learning difficulty. The woman decides whether she wants to attend the WIN Clinic or stay in other maternity programs. The clinic has been developed to provide extra support to women with intellectual disability and learning difficulty throughout their pregnancy and up to six weeks post delivery. Support can be provided in various ways such as individual childbirth education sessions or longer hospital stays to build new mothers’ confidence and skills before going home. Midwifery and social work support is available for up to six weeks after delivery to further develop parents’ confidence and to help them engage with community supports. The WIN Clinic is the only pregnancy care clinic in Australia that has been specifically set up to meet the needs of women with an intellectual disability or learning difficulty.

The WIN Clinic statistics are based on data collected on the thirty women who attended the Clinic in 2004. Of these thirty women, fifteen identified themselves as having a learning difficulty, such as not being able to read or just being slow to learn, and wanted the additional support the WIN Clinic could provide throughout their pregnancy. The other fifteen women were registered, or in the process of being registered, with Disability Client Services (DCS) as having an intellectual disability. DCS provides specialist services for people intellectual disability such as case management, respite care and, in some regions, specialist support for parents with intellectual disability. DCS eligibility requirements include evidence that before the age of 18 the person had an IQ of 70 or below and limited everyday living skills. It appeared that several of the women with learning difficulties would have been eligible for DCS but for various reasons they had never been registered and did not want to pursue this. Only people registered with DCS can access their services. The distinction between learning difficulty and intellectual disability is important for the significant difference in outcome of mother and baby staying together or being removed by Child Protection Services. Ironically, women with the intellectual disability label have been less able to access services and supports, this has contributed to higher rates of removal.

Disability perspective

There have been profound shifts in the values, policies and legislation affecting the lives of people with intellectual disability in the past thirty years. These shifts have been consistent across Western countries and are predominantly concerned with concepts of choice, inclusion, participation and citizenship (Bigby, 1999). Underpinning these concepts are the beliefs that people with intellectual disability should be valued as equal members of society who have the same rights as others (Bigby, 1999, p.19). Shifts in disability policies have meant that practices such as segregation and sterilization are slowly disappearing.

Exercising choice around fertility may have become a possibility for many women with intellectual disability but to make an informed choice women require accessible information about their sexual and reproductive rights and health. Pervasive beliefs that people with intellectual disability remain forever childlike (Swain, Goodfellow, Lee, Cameron, & Bennett, 2002) reinforce misconceptions, for example, that women with intellectual disability remain asexual and therefore do not need information or support around understanding their sexual and reproductive health and fertility choices. This information may also be withheld from women on the basis of mistaken beliefs such as the myth that giving young people information and education on sexuality will lead to them becoming sexually active sooner and, or indiscriminately (Gourlay, 1996).

Many women with intellectual disability or learning difficulties do not have the personal resources to gain accurate, appropriate information on their sexual and reproductive health if those around them do not recognise this need or assist. Almost half the women who attended the WIN Clinic did not receive pregnancy care until quite late into their pregnancy (more than 20 weeks). Although several women had deliberately avoided the health system for fear of coming to the attention of services, believing correctly this would lead to Protective Services involvement, and that, inevitably, their child would be removed. On the whole these women had not recognised changes to their bodies or the need for pregnancy care and it was their partners or families who first identified the pregnancy and organised for hospital appointments. While most women attending the clinic have been very happy with their, for most, unplanned pregnancies, clearly there needs to be more work done to ensure that women with intellectual disability are in a position to make informed and empowered choices around their fertility.

Parents with Intellectual Disability

Current values and policies about people with intellectual disability, as indicated above in Bigby (1999), support their right to choose to become parents and to be valued for doing so, like any other member of society. However, the reality for many of the women seen at the WIN Clinic is their motherhood is subject to disapproval, and too often leads to the removal of their babies, leaving the mothers with subsequent deeply held feelings of grief and loss. Removal has rarely been due to the mothers' lack of caring or trying to be the best possible parents. Often removal has been due to issues that could have been addressed with available and appropriate supports, for example finding more appropriate or adequate housing. Sometimes the women needed extra support with social tasks such as dealing with difficult neighbours, or practical tasks like managing the shopping or cleaning. Yet inadequacy in these areas became additional reasons for removal of children. McConnell and Llewellyn (1998, in Swain et al., 2002) referred to the 'false attribution' commonly experienced by parents with disabilities where structural issues such as poor housing, poverty, lack of education and supports are attributed to their disability. Many of the women attending the WIN Clinic did need extra time and support to learn parenting skills. The women with intellectual disability who did not have good social supports especially needed intensive support while they developed skills and adapted their lives to caring for a newborn. But service and community responses to supporting these new mothers frequently demonstrated a '...presumption that neglect / abuse will inevitably occur where a parent has a disability; that parenting deficiencies are irredeemable; and that appropriate parenting cannot be learned where a parent has a disability' (McConnell & Llewellyn, 1998 in Swain et al., 2002 p.144).

Many women who attended the WIN Clinic were reluctant to become involved with any service, often eventually stating their fear of Protective Services becoming involved.

Although attitudes are beginning to change, services, including some disability services, have been reluctant to accept referrals or to respond in a timely way pre-birth. Often services indicated that it was a Protective Services matter and they did not want to allocate their over-stretched resources into what they perceived as a lost cause. The result for some women was they then received too little support too late and fears of removal became self-fulfilling prophecies.

The Children, Youth and Families Act 2005 will commence in 2007. This new Act will mean Protective Services can, for the first time, act on pre-birth notifications of risk. There is a strong likelihood that a woman's intellectual disability will be conflated as her lacking the 'capacity to meet her child's needs' per the Act and pre-birth notifications become inevitable. Many women find this process very traumatic. As women with intellectual disability become aware of the increased scrutiny of their pregnancies and service interventions their fear of presenting for pregnancy care may similarly increase. The provision of accessible, flexible and supportive responses will become even more critical to ensure that women with intellectual disability do not avoid medical and pregnancy care altogether.

In their search of the literature Newman, Ziegler & Elliot (Newman, Ziegeler, & Elliot, 2005, p.9) highlight findings that challenge some of the commonly held negative beliefs about parents with intellectual disability. These findings include:

1. Children of parents with intellectual disability do not inevitably have intellectual disability.
2. Parents' IQ generally has little bearing on parenting ability or outcomes. Good parenting has not been clearly defined anywhere and usually comes down to subjective judgement made by professionals.
3. Parents with intellectual disability can provide adequate care but what this is and how it is assessed, is not clearly defined either. It has also been noted that parents with intellectual disability may only present to services when they are in crisis.

This therefore reinforces beliefs that these parents cannot cope or provide appropriate parental care.

4. It is not inevitable that parents with intellectual disability will abuse or neglect their children.
5. Parents with intellectual disability can learn parenting skills but it is important the training they receive is made suitable for their learning needs; for example provided over a longer period of time or delivered using visual resources for example.

Clearly parents with intellectual disability have to deal with negative perceptions and biases when seeking support or assistance. They are vulnerable because good parenting is not clearly defined and, as indicated above, is too often left to subjective judgements. Few professionals have been trained to work with people with intellectual disability and may misinterpret situations, or not realise the importance of presenting information in accessible and understandable ways. Professionals may believe they have conveyed information well when in fact the person with disability has not understood and who is then perceived as deliberately ignoring requests or choosing to behave inappropriately. In my experience, people with intellectual disability may initially present as though they have understood information but further questioning reveals they have not. Professionals' lack of understanding how to work well with people with intellectual disability this may lead to over-zealous response to potential risk and failure to take strengths into account. Failing to provide appropriate assessment and responses ultimately becomes a rights and equality issue (Booth, 2003). Booth described system abuse as:

> '…an unacknowledged scourge of families in which a parent has learning difficulty. It is rampant, pervasive and destructive of family life…(system abuse) is a crucial precipitating factor behind the high rates of child removal…Until we recognise its destructive effects, parents with learning difficulties will continue to receive rough justice and their children will get a raw deal.' (p.205)

Studies have found that parents with intellectual disability are disproportionately represented in child protection legal proceedings (Newman et al, 2005). Only one of the fifteen women with learning difficulty who delivered their babies with the WIN Clinic had her baby removed. This is equivalent to a removal rate of 7%. Twelve of the fifteen women registered with intellectual disability delivered their babies through the WIN Clinic. Seven of those twelve women, or 60%, had their babies removed soon after birth by Protective Services. This is paralleled by estimates in the UK that 40-60% of children are removed from parents with intellectual disability (Booth, 2003). At the end of a six week period of WIN Clinic support, another mother in this group had decided she was not able to continue parenting and her baby was removed. Thus nearly 70% of this group did not proceed with parenting. The contrast between the two groups is marked and, although there did not appear to be significant difference of intellectual ability of the women in either group, those who had DCS registration seemed to have far less self-confidence, self-reliance and independent living skills which impacted on their ability to take on mothering tasks.

The high rates of child removal from parents with intellectual disabilities and the discriminating and unresponsive practices that often lie behind this have been compared to the removal of children from indigenous Australian families and the creation of a ‘Stolen Generation’ (Booth, 2003). The social model of disability suggests there is a distinction between the ‘impairment’, or medical condition, and ‘disability’. It refers to the social environment that people with impairments experience, such as oppression, discrimination and exclusion (Oliver & Barnes, 1998). Mothers with disability experience much discrimination that focuses on their impairment and what is assumed they cannot do rather than on what they have been able to learn and achieve. As the persistent myths attest, the inability of many services to respond in appropriate, accessible ways and the failure to understand the learning needs of parents with intellectual disability is perceived as a shortcoming in the parents themselves.

Women attending the WIN Clinic

The women who attended the WIN Clinic give us a snapshot of their living situation, which raises concerns about the social and structural disadvantages and lack of informal and formal supports available to women with intellectual disability and learning difficulty living independently in the community. Nearly half of the women had experienced homelessness. One third of the women had neither a supportive partner nor family in their lives. This reinforced the need for flexible, accessible formal supports to be provided from other sources. Almost half the women had experienced domestic violence. Almost one third of women had been exposed to inadequate parenting and foster-care themselves and needed extra support to learn about parenting and interacting with their babies. This latter group of women were particularly fearful of Protective Services and several found their intervention raised traumatic memories.

By nature of their disability or learning difficulty the women who attended the WIN Clinic had less cognitive skill to deal with problems and stresses than most individuals, yet many were dealing with multiple, complex social and structural issues with few or no supports. Clearly, the additional complication of caring for a baby exacerbates any other issues which women confront them. That the women managed to cope as well as they did with such difficulties is testimony to both their strengths and skills. Nevertheless, the snapshot raises questions about the accessibility of services to this group of women and of how well young people with disabilities are being prepared for living an independent, adult life in the community. The women most affected by these issues were those registered with DCS. The degree to which they seemed to struggle more with independent living skills and have fewer supports than the non-registered women raises further questions about the long term effects of growing up with the label of ‘intellectual disability’ as there seemed to be little difference in other areas. Research is lacking and urgently needed to investigate the long-term effects brought about by putting an intellectual disability label on a person early in life. Certainly, the experience of women attending the WIN Clinic is indicative that a lot of education and support work is lacking. Both are necessary for this group of women to ensure they are in a position to make informed and empowered choices, whether around fertility or any other key area of their lives.

Service Supports

The Final Report of the Disability Parenting and the Law Project (Swain et al., 2002, p.3) found that for people with a disability in Victoria, the difficulties of parenting sometimes arose as a result of not being provided with the skills or supports needed and sometimes as a result of perceptions of being unable to parent adequately. These two difficulties seemed inextricable for most of the women from the WIN Clinic who had their baby removed. Not receiving timely, appropriate supports served to reinforce perceptions they could not parent adequately. Although all twelve women with intellectual disability wanted to care for their babies, only four mothers were still caring for their babies when WIN Clinic active involvement finished at six weeks. These four women had been able to access a service that specialised in working with parents with intellectual disability. This service provided flexible and intensive support when needed, with consultation and referral to other services as required. The professionals at this service were experienced in working with people with intellectual disability and were able to adapt practice and resources to meet the parents' learning needs. This is a crucial point as often when parents do receive services their learning needs are not recognised, they become reliant on support rather than developing knowledge and skills, and then they are judged as not capable of learning. The other key factor for these women was a helpful partner or family members. Mothers who had informal supports were perceived as requiring less service support and their informal supports were unofficially viewed as having supervision of, or being responsible for the babies' care.

As a group, sole mothers are discriminated against and motherhood in not given adequate state support (Oakley & Rigby, 1998, p.123). Sole mothers with intellectual disability are at a further disadvantage because of assumptions about their disability and their greater need for system supports, if they did not have adequate informal supports. The eight mothers with intellectual disability who had their babies removed did not have the informal supports to supervise their parenting or to fill the service support gap. Perceptions that the socially isolated women would not be able to parent adequately were further reinforced when appropriate services and supports were not provided because women had no way demonstrating they could develop skills or cope differently. It seemed the lack of supports in these women's lives was being viewed as reason for removal rather than responding to their support needs. There needs to be a rethinking of how services can work to support the increasing numbers in this group of women. There are models for working with very young mothers that could be adapted to assist women with intellectual disability. Such as services that provided intensive support and education about parenting, relationships and independent living skills could be given throughout the pregnancy, with support continuing for sometime following the birth of the baby, until such time as the mother is coping well emotionally and practically. Many of the socially isolated mothers attending the WIN Clinic had never received a comparable, comprehensive level of support or had access to any modelling of a caring relationship. This resulted in a concomitant negative impact on self-esteem and confidence to be parents.

Partner Support

Some of the women attending the WIN Clinic had very loving and supportive partners. Their support took many forms - helping women to attend appointments, coming to the delivery, and providing support and encouragement with learning parenting skills. Some partners would 'room in' with the new mother at the hospital so they too were learning parenting skills to support and share the parenting at home. These women thrived as mothers. With these informal supports and some extra community supports when needed, they appeared to manage parenting very well. Even when partners were not particularly supportive or were dealing with other complicating factors, such as mental illness or substance abuse, they were still presumed by Protective Services to be responsible for the baby's care and this was a key factor in the baby staying in their parents' care.

Almost half the women disclosed experiences of domestic violence. Many of those women had left their partners for the safety of the baby following the birth and because they had been made aware that staying with the partner would require Protective Services involvement and likely removal of the baby. The predicament for several of these women was that they had never learnt to be fully independent, for example how to manage their money, even to go shopping on their own or to use public transport to an unfamiliar place was very difficult. Their violent partners exploited this vulnerability and the woman's reliance upon them. Any opportunity the women had for learning new skills, or contact with services that could assist them, had been discouraged by these partners. These women were isolated and needed services that could respond, at least temporarily, in an intensive way. However their situation was compounded where services, such as refuges, did not have staff or resources to adequately support these women if they decided to leave the relationship. Supports for these women to be single mothers were even more limited. Because the women needed assistance to learn independent living skills they were seen as not capable adults and therefore not seen as capable of learning to parent. This is a common perception of parents with intellectual disability (Swain et al., 2002).

Family Supports

Almost half of the women attending the WIN Clinic had families that were involved with her and supportive of the pregnancy. Similar to supportive partners, families helped with practical tasks such as attending appointments, buying baby clothes and furniture, and generally assisted with preparations for the new baby. Sometimes a woman would move back in with her family after having the baby, staying until she felt confident with her parenting skills. Some families would roster themselves so someone was always available to the new mum if needed. However support was not always helpful. Many of the women had families, or sometimes partners, who undermined their capacity to learn and become competent parents by stepping in and taking over tasks before the women had enough time and practice to develop skills. In these families there was usually a long established pattern where family members took over any task that appeared difficult or took 'too much time' and the women had learnt to be acquiescent or not try. This learned behaviour in the women presented as lack of initiative, ability or caring when they seemed to hesitate to respond to their newborn and it can be very difficult to remedy when the family and home situation continued to reinforce this ‘learnt helplessness’. More generally, this learned behaviour was often the basis of why so many women had not fully acquired independent living skills and why having appropriate supports was so important. There is an important role here for services to advocate that women’s learning needs be met.

Some families have been hostile and rejected their daughter on learning of the pregnancy. One woman’s parents told her they would never speak to her again if she continued with her pregnancy to her partner of eight years. She continued with the pregnancy and went on to become a capable mother but to her great and ongoing distress her parents maintained their silence and rejection. They had still not spoken to her several months after their grandchild was born. Another young woman who was pregnant with her first baby complained that throughout her pregnancy she received several phone calls a day from her mother, telling her that she was not capable of being a mother and threatening to call Protective Services. This woman went on to successfully parent her baby with the support of her partner and, at times, minimal community supports.

Almost half of the women attending the WIN Clinic had mothers and female relatives to assist them with parenting. Several women relinquished their babies into the custody of female relatives. While having her child in the care of a relative can be positive, and may mean the mother has greater opportunity to be with her child than other arrangements, this can also be a very difficult and emotional situation for her to negotiate. These women did not have the personal resources to assert their rights and negotiate to see their children on a regular if not frequent basis, even in accordance with court orders. One woman’s parents had custody of her first child and had relocated without leaving a forwarding address. They refused all contact with the woman, including attempts by her social worker to organise a neutral meeting place. Another woman found that after the relinquishment to her parents they frequently gave her ultimatums to ‘be a good girl’, telling her that she should do what she was told, help with the housework, watch television and stop seeing the father of the baby. On several occasions in the six weeks following the birth of her baby they refused her access back into the home and told her she would never see her baby again because she had gone out without their permission. These mothers’ stories highlight the struggle and conflict and dis-empowered position women with intellectual disabilities and learning difficulty can experience in exploring their role as women and adults especially when their parents insist they remain in the role of children. The reactions of the parents of these WIN Clinic mothers also indicates how unprepared and under resourced many parents might feel to deal with the fact that their daughter with an intellectual disability will grow up to be a woman with the same needs and aspirations as other women in the community including, for some, the desire to become a mother.

Support to women separated from their babies

The grief experienced by women with intellectual disability who had their child (ren) and the opportunity to parent removed is very evident among the women coming to the WIN Clinic regardless of whether children have been put in the care of relatives or into permanent care. Contact with children has often broken down because many of the women struggle with using public transport and travelling to unfamiliar places or more generally with keeping appointments. Women also talked of having trouble negotiating manageable arrangements. Most had not received clear messages or understood why their previous babies or children had been removed. That several women indicated they would keep having babies until Protective Services let them keep one highlighted this issue. Often women expressed their grief as anger and hostility towards services and workers who may have any potential connection with removing their babies. None of these women appeared to have received counselling around their loss. Few had received (adequate) training or support to develop the parenting or independent living skills to redress the situations that were the reason for removal of previous children and were thus in the same position of likely removal in their current pregnancy.

Mothers with intellectual disability are particularly disadvantaged when their children have been removed and their parenting skills are being assessed on access visits of a few hours per week. The access visit often seems to take place outside the woman's home without a support worker or other supportive person. Such situations undermine the confidence and learning requirements of people with intellectual disability who need lots of practice over a period of time in their familiar environment with people they know and trust. Yet access visits that take place in unsupportive environments are often used as evidence to judge women as unable to parent their children.

Best Practice Responses

The response to parents with intellectual disability and learning difficulty is beginning to change and there are some appropriate and flexible services being developed. As a result some women are having positive pregnancy and parenting outcomes. The WIN Clinic works with pregnant and new mothers to make their hospital and early parenting experiences as supportive as possible. The numbers of babies being removed has been fewer in subsequent years.

There are specialist disability parenting services, such as the Family Outreach and Support Service, available to some women through Department of Human Services. This was the service that worked with the four mothers who were able to keep their babies. As part of the Healthy Start National Strategy for Children of Parents with Learning Difficulty service networks, or learning hubs, are being developed to bring together parenting and other services likely to work with parents with intellectual disability. Information and ideas on how to best support parents with disabilities are being exchanged through these networks. These initiatives are all crucial to moving away from the discriminating, deficit-model approach that has dominated responses to parents with intellectual disabilities. While there is still clearly also a need for specific training of the professionals who work with these parents. Considerable research (McConnell & Llewellyn, 2002; McConnell, Llewellyn, & Ferronato, 2002; McConnell, Llewellyn, Mayes, Russo, & Honey, 2003) already exists which demonstrated we need more flexible and accessible ways of supporting women with intellectual disability who have become mothers. The alternative is to continue the system abuse response and confront the consequences of another population of stolen children.

References

Bigby, C. (1999). International trends in intellectual disability policy in the late 1990's. In E. Ozanne (Ed.), *Reframing Opportunities for People with Intellectual Disability* (pp. 366). Melbourne: University of Melbourne, School of Social Work.

Booth, T. (2003). Parents with learning difficulties and the stolen generation. *Journal of Learning Disabilities, 7*(3), 203-209.

McConnell, D., & Llewellyn, G. (2002). Stereotypes, parents with intellectual disability and child protection. *Journal of Social Welfare and Family Law, 24*(3), 297-317.

McConnell, D., Llewellyn, G., & Ferronato, L. (2002). Disability and Decision-Making in Australian Care Proceedings. *International Journal of Law, Policy and the Family*(16), 270-299.

McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003). Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual & Developmental Disability, 28*(2), 122-134.

Newman, C., Ziegeler, R., & Elliot, S. (2005). Issues Facing Parents with Intellectual Disability. *Interaction, 19*(1), 7-15.

Oakley, A., & Rigby, A. S. (1998). Are men good for the welfare of women and children? In J. Popay & J. Hearn & J. Edwards (Eds.), *Men, Gender Divisions and Welfare*. London: Routledge.

Oliver, M., & Barnes, C. (1998). *Disabled People and Social Policy*. London: Longman.

Swain, P., Goodfellow, J., Lee, J., Cameron, N., & Bennett, W. (2002). *Pride and Prejudice. Final report of the Disability Parenting and the Law Project*. Melbourne: Disability Discrimination Legal Service Inc.

Useful websites:

Parenting Resource Centre *raising children well*

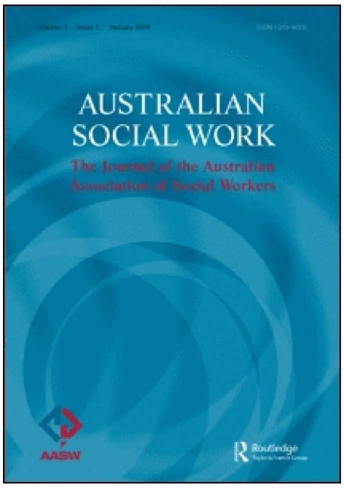
http://www.parentingrc.org.au/vp/projects/current_projects.php

Healthy Start *a national strategy for children of parents with learning difficulties*

http://www.healthystart.net.au

Australian Families and Disability Studies Research Collaboration, School of Occupation and Leisure Sciences, University of Sydney

http://www.afdsrc.org



Australian Social Work
Publication details, including instructions for authors and subscription information:
http://www.informaworld.com/smpp/title~content=t725304176

Women with Cognitive Impairment and Unplanned or Unwanted Pregnancy: A 2-Year Audit of Women Contacting the Pregnancy Advisory Service

Brenda Burgen [a]
[a] Royal Women's Hospital, Melbourne, Australia

To cite this Article Burgen, Brenda(2010) 'Women with Cognitive Impairment and Unplanned or Unwanted Pregnancy: A 2-Year Audit of Women Contacting the Pregnancy Advisory Service', Australian Social Work, 63: 1, 18 — 34
To link to this Article: DOI: 10.1080/03124070903471033
URL: http://dx.doi.org/10.1080/03124070903471033

Australian Social Work
Vol. 63, No. 1, March 2010, pp. 18–34

Women with Cognitive Impairment and Unplanned or Unwanted Pregnancy: A 2-Year Audit of Women Contacting the Pregnancy Advisory Service[1,2]

Brenda Burgen
Royal Women's Hospital, Melbourne, Australia

Abstract

Little is known about the experience of women with cognitive impairments (intellectual disability and acquired brain injury) in relation to unplanned or unwanted pregnancies. Records of the Pregnancy Advisory Service (PAS) at the Royal Women's Hospital across a 2-year period were examined. Details of 20 women with cognitive impairments, who had contacted PAS for support with an unplanned or unwanted pregnancy, were found. Many of these women had faced significant barriers to reproductive choices. The majority of the women had needed someone to facilitate their first contact with PAS; one quarter had contacted PAS too late for the option of the abortion they were seeking; one quarter were in significant conflict with their support people over the pregnancy; almost half of the women contacted PAS significantly late in their pregnancy; and one quarter (more than half of those who already had children) were currently involved with child protection services. The audit suggests that women with cognitive impairments need more accessible information on sexual and reproductive health, and assistance to access pregnancy information and services. It is important that social workers and other professionals who work with women with cognitive impairments be aware of their greater vulnerability and often complex social situations, and adopt a proactive as well as supportive approach when working with these women.

Keywords: Women; Disability; Contraception; Health; Social Work

Until recently, the failure to acknowledge women with intellectual disability as sexual beings has resulted in many barriers, such as restrictive institutional living and lack of privacy, which has prevented them from exercising their right to engage in adult, sexual relationships. Girls and young women with intellectual disability were once routinely sterilised to prevent them from becoming mothers; an abuse of their

---

[1] This paper was accepted for publication under the editorship of Professor Tim Stainton and Professor Lesley Chenoweth.

[2] The audit was undertaken as a staff member of the Royal Women's Hospital, Melbourne.

Correspondence to: Brenda Burgen, The Centre for Developmental Disability Health Victoria, Monash University, Building 1, 270 Ferntree Gully Road, Notting Hill, Vic, 3168, Australia. E-mail: Brenda.burgen@med.monash.edu.au

Accepted 6 November 2009

ISSN 0312-407X (print)/ISSN 1447-0748 (online)
DOI: 10.1080/03124070903471033

fundamental human right to maintain bodily integrity that made them even more vulnerable to sexual assault, sexual exploitation, and sexually transmitted infections (Brady, 2001). Although many barriers still exist, policy and program changes over the last two decades have meant more freedom for women with intellectual disabilities to engage in sexual relationships and greater opportunities to take control of their sexual and reproductive health. An outcome of such changes is the increasing number of women with intellectual disabilities who experience pregnancy, childbirth, and motherhood (Tarleton, Ward, & Howarth, 2006). There is a dearth of literature about these issues in relation to women with acquired brain injuries, which meant that although they were included with women with intellectual disabilities in the study reported here, the literature reviewed is solely focused on the latter group. It is also noteworthy that much of the literature is dated and little research has directly addressed issues of unplanned or unwanted pregnancies in women with intellectual disabilities. It can be argued that despite clinical differences both intellectual disabilities and acquired brain injuries are cognitive impairments, so there is likely to be some similarity in the issues and support that women require from professionals, and that some aspects of the literature may be relevant to both groups.

Research on women from the general population has found that up to 50% of pregnancies in Australia are unplanned (Marie Stopes International, 2006) and it is estimated that "around one-third of all Australian women are having at least one abortion during their reproductive years" (Bayly, 2005, p. 50). The experience of unwanted or unplanned pregnancy for women with intellectual disability is raised anecdotally in the literature. For example, McCarthy's (2009) UK study on contraception and women with mild and moderate intellectual disabilities found there had been a total of 13 pregnancies among the 23 women in the study that resulted in 9 children, 2 stillbirths and 2 abortions. McCabe and Cummins (1996) conducted a small study in Australia that examined the sexual knowledge, feelings, needs, and experiences of people with mild intellectual disabilities living in group homes. They found that 61% of the 18 women with mild intellectual disabilities in the study, whose mean age was 25.2 years, had experienced pregnancy, compared with 20% of the 32 women in the control group who were first-year psychology students with a mean age 20.6 years. They did not discuss the women's experience of pregnancy or indicate the results of the pregnancies, and there was no discussion of parenthood.

It is difficult to estimate how many women with intellectual disabilities might be affected by unplanned or unwanted pregnancy. Approximately 1% to 3% of people in the Victorian population have intellectual disabilities and only half of the potentially eligible population are registered to receive specialist disability government services and programs (Bigby & Ozanne, 2001; Victorian Auditor General, 2000). Therefore, it is likely that some women with intellectual disabilities may not receive support from disability services when they become pregnant. When they first contact health and welfare services they may not identify that they have a disability and this may not be immediately obvious to workers unfamiliar with this group.

The term "intellectual disability" has various meanings, and definitions range from the strict criteria of a sub-average general intellectual functioning and significant deficits in adaptive behaviour, as set out in Victorian legislation, to self-report of general learning difficulties (Disability Act, 2006). It has been argued, in relation to pregnancy and parenting in particular, that many people who self-report learning difficulties have similar support needs, socioeconomic characteristics, and vulnerabilities to those who meet the specific eligibility criteria to receive disability-specific services (McConnell, Mayes, & Llewellyn, 2008). It is questionable whether generic services recognise or meet the greater learning and support needs of either the self-reporting group or those who are eligible but choose not to use disability services. The literature suggests that women with intellectual disabilities face a number of additional barriers and issues around unplanned or unwanted pregnancies, many of which stem from difficulty accessing health services, inadequate or inappropriate supports, and lack of accessible information.

Access to Contraception and Pregnancy Information

The small amount of research that examines the knowledge of adolescents and adults with intellectual disabilities about contraception, pregnancy, and abortion indicates their knowledge is poor (Cheng & Udry, 2003; Galea, Butler, Iacono, & Leighton, 2004; Servais, 2006). McCarthy (2009) found the majority of the 23 women in her study lacked basic knowledge of contraception even though all were either current or past contraception users. Despite relatively high levels of ability and social functioning, almost half of the women lacked knowledge about reproduction. None of the women in this study received accessible information about contraception from their general practitioner or family planning clinics. Overall, the literature suggests that little, if any, information about contraception and sexual and reproductive health is given to people with intellectual disabilities, especially those in younger age groups (Cheng & Udry, 2003, 2005).

People with intellectual disabilities need information to be presented in a more simplified form across a longer time frame than the general population. It has been suggested that accessible education and information on sexual and reproductive health should be taught and reiterated to women with intellectual disabilities across their reproductive life course (Ditchfield & Burns, 2004). However, in figures analysed from the US National Longitudinal Study of Adolescent Health (1994–95), Cheng and Udry (2003) found that teenagers with intellectual disabilities received less classroom instruction on pregnancy, and less instruction and information from parents than their non-disabled peers. Fewer parents of children with intellectual disabilities discussed sex, pregnancy, and STIs with their child compared to other parents (Cheng & Udry, 2003). Not surprisingly, they found that teenagers with intellectual disabilities had "largely incorrect knowledge of birth control and human fertility" (Cheng & Udry, 2003, p. 37). This study also found that rates of adolescent boys and girls with intellectual disabilities having sex without their parents' knowledge was respectively "2.4 and 2.6 times" higher than in other young people.

Cheng and Udry (2005) raised concern that adolescent girls with intellectual disabilities are less likely to use contraceptives and thus are at high risk of contracting STI's and of unwanted pregnancy.

Poor Knowledge of the Connection Between Menstruation and Fertility

In addition to their overall poor level of knowledge in sexual and reproductive health, some studies anecdotally indicate that many women with intellectual disabilities do not understand the connection between menstruation and fertility (Ditchfield & Burns, 2004; McCarthy, 2002). For example one woman in Ditchfield and Burns' study thought her "hormones would be wanting" her to have children and: "I don't know how you get pregnant. There's a link between periods and getting pregnant but I don't know what it is" (Ditchfield & Burns, 2004, p. 29). Another woman who had three children reported: "I know we have periods because of babies . . . but, well, I'm not sure how" (Ditchfield & Burns, 2004, p. 29).

Beckmann, Hiller, and Jones (1996) suggested that women who have experienced pregnancy are likely to recognise subsequent pregnancies earlier. However, this expectation may not be applicable to women with intellectual disabilities because an understanding of the connection between menstruation and pregnancy can be critical to early recognition of pregnancy. This is illustrated by the following comment from a woman who had several children: "If you don't have periods then it can stop you getting pregnant and I wasn't on my monthly so I don't know . . . I didn't know I was pregnant for a long time" (Ditchfield & Burns, 2004, p. 29). Ditchfield and Burns suggested it was likely that information about menstruation and fertility had been presented to the women in their study but in a way that was not easily understood and thus not retained. The need for ongoing and accessible education is supported by a 4-year follow-up study by Elkins, Kope, Ghaziuddin, Sorg, and Quint (1997) of the sexuality counselling, education, and ongoing communication provided through their gynaecology clinic to 103 people with a range of intellectual disabilities. They found that only one unwanted pregnancy had occurred across the 4-year period. This finding suggests that a comprehensive approach that provides accessible information and counselling, health services, and support can assist people with intellectual disabilities to better manage their sexual and reproductive health.

Recognition of Pregnancy

Knowledge of contraception, reproduction, and pregnancy are necessary to early recognition of pregnancy. Early recognition of an unplanned or unwanted pregnancy can be of critical importance in giving women time to consider their situation and to seek out pregnancy counselling and options if they wish. From mid-trimester, or 12 weeks gestation, body changes and signs of the pregnancy become increasingly apparent and this can impact on decision-making. Service providers place time limits on the gestation at which they will provide abortions, and having a short time to think through options may also impact on decision making. Time limits vary according to service provider and the legislation on abortion varies across the states and territories of Australia. While some private clinics perform later-term abortions than clinics in the public health system, the associated expenses may pose a barrier to women who live on Disability Support Pensions.

Several of the factors associated with the late recognition of pregnancy may have particular relevance for women with intellectual disabilities. While an association between sociodemographic factors and delay in seeking abortion has been disputed, lower levels of education appear to be an important influence (Beckmann et al., 1996). As already outlined, lack of accessible information and poor knowledge of contraception, reproduction, and pregnancy are significant issues for many women with intellectual disabilities. In addition, women who have not experienced pregnancy before may remain unaware of pregnancy until later in gestation (Beckmann et al., 1996). This lack of awareness may be particularly so for women with intellectual disabilities who have little understanding of pregnancy.

Women who use contraception erratically may have little "expectation" of pregnancy, which in turn contributes to denial and delayed recognition (Beckmann et al., 1996). The poor memory and organisation skills associated with intellectual disability, together with a limited or confused understanding of contraception, makes it more likely that contraception use will be erratic unless women are receiving assistance. It could be argued that the disproportionate use of Depo-Provera, a longer acting contraceptive administered by injection, in women with intellectual disabilities should reduce erratic contraceptive use. However, the use of Depo-Provera seems to be less in women with milder intellectual disabilities, possibly due to their capacity to participate in the contraceptive decision-making, and also less in women not living in institutions (Servais et al., 2002). The high rate of pregnancies experienced by women with mild intellectual disabilities in the McCabe and Cummins (1996) study highlights that this milder group may be particularly at risk of unplanned pregnancy.

Abortion

The topic of unplanned or unwanted pregnancy, or both, and abortion has received little discussion in the disability literature (Servais, 2006). Attard's (1988) observations of working with women with intellectual disabilities was the only paper found that directly reflected on the impact of unplanned pregnancy and abortion of this group. The issues she raised remain relevant and included: confusion experienced by women who received inadequate counselling and information about their pregnancy; and the unavailability of necessary time to accept the pregnancy and think through options due to late recognition.

Many women with mild and moderate intellectual disabilities are able to understand and give informed consent to medical procedures. When the woman has a more severe intellectual disability and cannot give informed consent, legislation governs the provision of medical treatment, although its nature varies in each jurisdiction. In Victoria, the Guardianship and Administration Act 1986 provides for a "Person Responsible" in the case of people who cannot give informed consent. The

Person Responsible can consent to most medical treatments, for example, contraception, but cannot give consent for an abortion that is defined as a "special procedure". Consent for an abortion, when the woman is unable give her own consent, must be sought through the Victorian Civil and Administrative Tribunal[3]. If working with a woman whose capacity to give informed consent to an abortion is questioned, ethical practice would demand that the woman's capacity to have given informed consent to sex also be queried and an assessment of her safety from sexual assault be conducted.

Decision-making

Pregnancy decision-making is made in the context of social, family, and partner influences. Much of the literature indicates there is social disapproval on many levels for women with intellectual disabilities in relation to having and parenting children. It is claimed that the opportunities for people with intellectual disability to parent their children are limited by prejudice and unequal access to resources, especially to appropriate services and professional support (International Association for the Scientific Study of Intellectual Disability, Special Interest Research Group, 2008). It is argued that when people with intellectual disabilities do have children they encounter systemic abuse and their children are removed at high rates (Booth, 2003; McConnell & Llewellyn, 2002). Kallianes and Rubenfeld (1997) discussed the historical and political context of coercion of women with disabilities into abortion and the discouragement of them from being sexual or from childbearing. The sterilisation of girls and young women with intellectual disabilities continues in Australia (Brady, Britton, & Grover, 2001). McCarthy (1998) in a study of 15 women with intellectual disabilities who were using, or had used, contraception found that only one of these women seemed to exercise control or choice over contraception use, which reflects the ongoing pressure to control the fertility of women with intellectual disabilities. In McCarthy's later (2009) study, most of the women did not think it was within their control to stop using contraception. Attard (1988) reflected on working with women with intellectual disabilities who had been pressured by family to have abortions and the ongoing grief some women experienced afterwards.

Partners have significant influence over women's choices, while mothers and sisters are important indirect influences, according to an Australian study of young women's decision to continue or terminate their pregnancy (Evans, 2001). Women with intellectual disabilities are often reliant on family or partners for assistance with daily living tasks, so fear of disapproval or lack of social support, identified by Beckman et al. (1996) as major reasons for women taking longer to reach their decision, might have particular impact. Women with disabilities experience higher rates of domestic violence than other women, due to their increased vulnerability from factors such as reliance on others for care and support, social isolation, inadequate or inappropriate services and supports, or both, and the nature of disabilities (Innes, 2007).

---

[3] Further details are available from the Office of the Public Advocate: publicadvocate.vic.gov.au

Many women with intellectual disabilities are dealing with inadequate social support and often difficult and complex social issues prior to the pregnancy, which may impact on their decision-making. An audit of the pregnancy care clinic at the Royal Women's Hospital (RWH), Melbourne, which was developed to provide extra support for women with intellectual disabilities, revealed that many of the women had experienced difficult social issues. For example, one third of the 30 women either had no partner or family, or an unsupportive partner or family, almost half of the women had experienced homelessness, and almost half of the women disclosed experiences of domestic violence (Burgen, 2007).

Pregnant women have been identified as a group at greater risk of experiencing domestic violence (Phillips & Park, 2004). In a study of 400 pregnant women from a diverse range of backgrounds attending the RWH, it was found that 20% experienced violence for the first time or that it continued throughout their pregnancy, with 6% experiencing increased violence (Walsh, 2008). An important finding from Walsh's (2008) study is that the women did not report the violence to their health care professionals. Pregnancy may be one of the few times that women living in violent relationships come in contact with formal services, thereby providing one of the few opportunities to receive information and support to improve their living situation. However, women with intellectual disabilities may not be aware of their rights, or that they can seek assistance if they are in violent relationships, so their situation may need careful exploration and proactive interventions from pregnancy counsellors, social workers, and health care professionals.

Access to Health Services

Timely access to abortion services is related to women's confidence and ability to seek out the health service they need rather than to prior knowledge of abortion services (Beckmann et al., 1996). It has been well established that people with intellectual disabilities have poorer access to health care compared to the general population, even though their health needs are greater (Harrison & Berry, 2006; Jenkins & Davies, 2006). McCarthy (2009) found that the majority of women with intellectual disabilities attended medical appointments accompanied by staff or family and that the women felt this boosted their confidence, but even so, it seemed that there was little communication between the women and their medical practitioners.

Murphy's (2006) study highlighted a number of difficulties people with intellectual disabilities experienced in accessing health services. Difficulties can begin before the appointment, such as dealing with telephones or recorded messages, or both, and the ability to take down appointment information over the phone. These are all potential barriers to women with intellectual disabilities seeking out appointments, information, and counselling or support services, especially from unfamiliar and busy hospital or medical centres. A woman with an unplanned pregnancy who does not have someone supportive to assist her with making and attending medical appointments may not be able to access timely pregnancy advice and support.

Audit of the Pregnancy Advisory Service Database

The Royal Women's Hospital (RWH) in Melbourne, Australia is a tertiary hospital specialising in women's health and is the major public provider of abortions in the state of Victoria. The Pregnancy Advisory Service (PAS) responds to all initial enquiries to the RWH about unplanned or unwanted pregnancy and provides information about pregnancy options; parenting, adopting, and abortion. It also provides advocacy and referrals to support services and make medical appointments and bookings at the woman's request. Counselling is an optional, free service offered by PAS to all women. The PAS accepts self-referrals and referrals from health professionals; in the latter case the woman concerned is given the opportunity to talk with the PAS advocate and to confirm her wish to attend the appointment.

For some time the PAS staff and social workers who assisted with counselling had reported anecdotally that providing a service to women with intellectual disabilities or acquired brain injuries was a complex and resource-intensive contact, requiring specialist knowledge. Women in this group also seemed to be contacting PAS with pregnancies at later gestations than other women, which had implications for decision making and for service delivery, such as requiring urgent appointments or crisis responses. It seemed that women with intellectual disabilities and acquired brain injuries over 18 weeks gestation were contacting the RWH about unplanned pregnancies more frequently than other women. At that gestation, an abortion was not available at this hospital.

PAS staff and social workers raised concerns about the issue of informed consent, should it arise, in relation to women with severe intellectual disabilities and requests for an abortion. Finally, there was concern that women with disabilities and impairments might be missed in the PAS intake process and therefore not offered extra assistance in a timely way. This concern was drawn from experience in the maternity system, where sometimes women's disabilities and impairments only became apparent to medical staff when the women were staying on the maternity ward.

The author, who was social worker for the pregnancy care clinic for women with disabilities, and the managers of the PAS and the Women's Social Support Services submitted an internal grant proposal to conduct a project that would address the issues that had been raised.

Aim of the Project

The primary aim of the project was to conduct a literature review and an audit of the PAS database that would develop evidence-based understanding of the experiences of women with intellectual disabilities and women with acquired brain injuries in relation to unplanned or unwanted pregnancy. From this understanding, service and practice responses that would best support this group of women could be developed to assist PAS and other RWH staff in their practice. Primary outcomes that would be informed by the data were a Clinical Practice Guideline and a resource booklet to assist clinicians working with women with intellectual disabilities or acquired brain injuries.

Method

Data are routinely collected and entered into a database by the PAS staff. The data include demographic and social details, the pregnancy circumstances, and the options being considered. Details of whether women had disabilities were recorded in the database from 2005. The database was searched to find women who had been recorded by PAS staff as having intellectual disabilities or acquired brain injuries. Eighteen women with intellectual disabilities and two women with acquired brain injuries were located across a 2-year period, from 2005 to 2007. Women with acquired brain injuries were included in the audit as having, from a service perspective, similar issues and needs to women with intellectual disabilities. From here on these two groups of women will be referred to together as women with cognitive impairments.

The case notes written by PAS staff on their work with the women identified through the database were then located. The notes indicated that the cognitive impairments had been reported either by the woman or the person supporting her. Apart from basic demographics found in the database, the information collected and recorded in the case notes was largely at the PAS staff member's discretion; therefore, the range of detail recorded differed from woman to woman. In several cases, where the woman had ongoing contact with the RWH, other clinician notes were consulted for further detail.

A noteworthy issue that arose in gathering data for the audit was to find that data entered by social workers, who used a different database from the PAS staff, did not capture whether or not women had disabilities. This is significant because if women are in crisis and cannot be assisted by PAS because their unplanned pregnancy is over 18 weeks gestation, they are often directed to the Social Work Department without being recorded as a PAS patient and entered into the PAS database. Therefore, it was impossible to find these women and include their details in the audit. Consequently, there were more women with cognitive impairments who had contacted the RWH and were too late to obtain the abortion than is presented in the data.

Results and Discussion

Non-identifying demographics, circumstances and outcomes were collected and collated for the audit. Descriptive statistics have been drawn and themes from qualitative data presented. A number of significant issues for women with cognitive impairments emerged from the data. Where possible, outcomes for women with cognitive impairments have been contrasted with data collected for a 2006 unpublished report of all PAS service users. Table 1 sets out the findings.

Table 1 Demographics and outcomes for women identified as having cognitive impairments and who attended PAS appointments 2005–2007

Demographic or outcome for women with cognitive impairment	All women* drawn from the 2006 (unpublished) PAS database	Women with cognitive impairment, drawn from PAS database 2005–2007
	Approximately 4,500 women	Across a 2-year period, 18 women with intellectual disability and learning difficulty and 2 women with acquired brain injuries
A higher percentage were from a younger age group	44% of women were aged 25 years and younger	75% (15 women) were aged 25 years and younger
Living arrangements and forms of support	Not analysed	All lived in the community with partners, parents or on their own 50% (10 women) received formal service support
A similar percentage of women had children	42% of the 5462 women who contacted PAS in 2007 had children (figure for 2006 not available)	40% (8 women) had children. Only 3 of those women (37%) were primary carers of their children
Assistance used to contact the PAS	Not analysed	75% (15 women) were assisted to make contact by (7 mothers, 7 workers and 1 friend)
Late recognition of pregnancy	20% of women contacted PAS after 12 weeks gestation	45% (9 women) contacted the PAS at 12 weeks gestation or later
Pregnancy recognised too late for option of abortion	Almost 2% of women were over the gestational limit. (Includes some of the women with cognitive impairments)	25% (5 women) were at 18 weeks or greater gestation, too late to proceed with an abortion through the RWH and public health system
Decision-making: delay to contact the PAS after pregnancy is recognised	Not analysed	20% (4 women) contacted the PAS after four weeks or more after the confirmation of their pregnancy
Violence and Sexual assault	Not analysed	20% (4 women) discussed domestic violence issues and two stated their pregnancies were due to sexual assault by estranged partners. A further 2 women described non-consensual circumstances around their pregnancy.
Conflict over reproductive choices	Not analysed	25% (5 women) indicated their wishes conflicted with family/partner/supports.
Fewer women proceeding with an abortion	80% of women proceeded with an abortion	50% (10 women) proceeded with an abortion

*These data are not representative of all Victorian women dealing with unplanned or unwanted pregnancy; rather they represent a particular group of women contacting PAS at a particular time period.

Younger Age Group

Three quarters of the women with cognitive impairments were 25 years or younger. This compares with less than half of all PAS service users and supports concerns raised by Cheng and Udry (2003, 2005) that young women with intellectual disabilities are at great risk of unplanned and unwanted pregnancy. Younger women in general may face increased issues with unplanned pregnancy, such as developmental readiness to become a parent, financial and housing stability, and having supportive and stable relationships established. Potentially, these issues may be further complicated if the young woman has a cognitive impairment.

Contacting the PAS

It was significant to find that most women relied on their mother or a worker to make the initial contact with the PAS on her behalf. It is also possible that several of the five women who made the initial phone call to the PAS had workers present and assisting them to make the call without the PAS advocate being aware. That the majority of women had someone assist them with contacting the PAS is similar to the finding in McCarthy's (2009) study that only 5 of the 23 women went to their appointments alone and that the majority of women were happy for the staff or family member to act as "a kind of intermediary or interpreter" (p. 366) in the appointment. It also supports findings that indicate accessing health services presents difficulties for people with intellectual disabilities (Murphy, 2006). One woman who initiated contact herself did this through a RWH social worker who she knew and trusted, which reinforces the importance of people with cognitive impairments having established relationships with professionals and familiarity with services. This finding suggests that women's access to services such as the PAS may be dependant on the willingness and ability of others to facilitate the appointment.

Service Response

Half of the women in the audit referred to a service or multiple services that were assisting them in various ways. Only 1 woman used a generic support service and 5 women were receiving disability specific services. None of the women lived in intellectual disability residential services.

The main generic service in contact with the women was the government Child Protection service, which had involvement with 5 of the 8 women who had children. The children of 3 women had been removed and another 2 women indicated their children were being cared for by family members. This finding supports concern about the high level of child protection interventions that parents with cognitive impairments receive (Booth, 2003; McConnell & Llewellyn, 2002). It may also be highlighting that having a child creates one of the main entry points into services for women with cognitive impairment. This may be one of the few times that women come into contact with the service system and their need for services and support recognised or reaches crisis point, or both. Women with cognitive impairments are often socially isolated with few adequate or appropriate supports (Burgen, 2007; Innes, 2007). This may become a critical issue when taking on the tasks of parenting, especially if a sole parent. The majority of women were assisted to contact PAS, which underscores the general level of support most women required. That the general support needs of mothers with cognitive impairments need to be recognised and addressed by disability or support services other than Child Protection was indicated by finding that two of the women received assistance from the child protection worker to make contact with the PAS. This is an ambiguous situation for the workers and also for the women, who may have difficulty in fully understanding the workers' role and responsibilities. One woman, in particular, believed her worker had a vested interest in stopping her from having another baby, which impacted on her pregnancy decision-making.

Delayed Recognition of Pregnancy

Almost half of the women in the audit, including women who had previous pregnancies, recognised their unplanned pregnancy from 12 weeks onwards. This is more than double the comparison of women from the general population. Twelve weeks is becoming late in terms of seeking information and pregnancy options. The audit did not reveal why the women recognised and responded to their pregnancy quite late but it could be speculated this was due to having less knowledge and understanding about pregnancy signs as was indicated in the literature.

It was concerning to find one quarter of the women contacted PAS too late to receive the abortion they were seeking through the public health system. As indicated earlier, the actual number of women who contacted PAS too late should be greater but the identifying data were not collected. A further finding was that 2 of the 5 women who recognised their pregnancy at 18+ weeks had previous experience of pregnancy, as both of these women had several children. This, along with anecdotal literature, suggests the general expectation that women recognise subsequent pregnancies at earlier gestations should be questioned when working with women with cognitive impairments. The above two women received maternity care at the RWH. They indicated initial confusion and disbelief about the signs of their pregnancies and reported leading chaotic lifestyles with few informal or formal supports, all of which seemed to have contributed to late recognition and response to the unwanted pregnancies. The women remained very distressed and angry about continuing their pregnancies for the duration of their pregnancies. After delivery, one woman chose to have no contact with her baby and the other woman's baby was removed by services who were involved with her other children.

The outcomes for the 20 women with cognitive impairments contrasted with the outcomes for women who contacted PAS in 2006. Only 50% of women with cognitive impairments proceeded to have abortions, compared with 80% of women from the PAS population. The difference in outcomes is largely due to 25% of the women with cognitive impairments being unable to obtain an abortion through the RWH, because they were more than 18 weeks pregnant. If these women had been able to proceed with the abortion they were seeking, the outcomes for the women in this audit would have been similar to that of the general population of women who approached PAS.

Decision Making and Delayed Contact with the PAS

Most women in the audit appeared to have contacted PAS within several days, if not immediately, on having the pregnancy confirmed. Therefore, it seemed significant to find four women who indicated they had known about their pregnancy for 4 weeks or longer before the PAS was contacted. The common presenting theme for these women was the conflict between their wishes about the pregnancy and the views of family, partner or, for one woman, workers. Two of the women who delayed contact with PAS described feeling pressured to abort the pregnancy when they wished to continue. One of these women delayed contact and decision-making, hoping her partner would change his mind and become supportive. The other woman decided that, even though she initially had not wanted to continue the pregnancy, she would continue because of what she perceived as pressure from workers to abort. The two other women strongly expressed that they did not want to continue their pregnancies, but it was only through the intervention of their workers that appointments were arranged and the women assisted to attend PAS in order to discuss their pregnancy options. Two of these four women had identified being in violent relationships.

The reliance of women on the ability and willingness of others to support them to access the PAS to discuss pregnancy options has already been highlighted. The two women who felt pressured to have an abortion were able to use PAS contact to receive support and advocacy to continue the pregnancy if they chose. Another woman, who did not delay contact with the PAS, also used the PAS to receive support and advocacy to continue the pregnancy she wanted and received assistance to leave a violent relationship. On the other hand, the two women who did not want their pregnancies to continue would have received no options counselling or exercised any choice about their pregnancy without their workers' proactive interventions.

There is a history of coercion and pressure on women with cognitive impairments to not have children and ongoing social disapproval when they become parents. However, this audit raises the different issue that some women with cognitive impairments experience pressure or withholding of support so that they continue with unwanted pregnancies. Given the literature on the social isolation, lack of supportive relationships, and reliance on others to assist with appointments, the vulnerability of women with cognitive impairments to this form of coercion is concerning.

Violence

Partner violence was clearly identified by 4 of the women, 2 of whom indicated their pregnancies were the result of sexual assault. The pregnancy circumstances of a further 2 women strongly indicated non-consensual sex although the women did not clearly state this. Assistance was provided by PAS to 2 of the women around intervention orders and referrals to a domestic violence service and a refuge. The other 2 women maintained involvement in long-term relationships that were violent on many levels, but were being assisted with this by other services. This finding indicates that the women in this audit are experiencing violence at a similar level, if not greater, than other pregnant women; for example, the 20% of pregnant women who experienced violence through their pregnancy as found in the Walsh (2008) study.

Implications of the Study

While many women experience unplanned or unwanted pregnancies, a number of specific issues arise in this area for women with cognitive impairments. The high percentage of younger women affected by unplanned or unwanted pregnancies, the high percentage of women recognising their pregnancy late, and the one quarter of the women too late for the abortions they were seeking are important issues. The literature indicates that more and accessible sexual and reproductive health information and education needs to be targeted to this group of women. The audit provides evidence that, at the very least, women with cognitive impairments need to be better informed about contraception and how to recognise the signs of pregnancy and how to respond in a timely way. The literature indicates that information and education needs to be repeated and reviewed with all women with cognitive impairments across their reproductive years, including women with previous pregnancy experiences. Many people, especially younger people, with cognitive impairments attend post-secondary courses. This may be the ideal venue through which women with cognitive impairments can be reached to ensure they receive education about contraception and pregnancy. Other issues such as preparation for independent living and for becoming parents, and information on rights in relationships and that violence is not acceptable, might also be addressed.

Many women with cognitive impairments need assistance to attend health services and medical appointments. Social workers and other professionals may need to facilitate these appointments and ensure that women receive accessible information on contraception, pregnancy, and pregnancy options. A proactive approach may be needed as a woman’s lack of knowledge may mean she does not realise what she needs to do or ask without some prompting or prior discussion.

Through this audit it was found that women with cognitive impairments, like other women, can experience conflict with family and partners over the pregnancy decision-making. Some women experienced pressure and threats of violence through pregnancy; others experienced withdrawal of support and did not receive the assistance they needed to seek out options and to exercise their choice. Again, being proactive about the rights and welfare of women with cognitive impairments is essential to good practice as many women may not be able to identify an abusive situation, or know where to ask for the assistance or the services that they need. Interviewing women on their own to explore safety issues and possible conflicts with support people's wishes is important practice in providing counselling and support. Overall, the higher rates of violence against women with cognitive impairments and their greater reliance on others, which increases their vulnerability, are cause for considerable concern.

The aim of this project was to improve service and practice responses to better support women with cognitive impairment. The development of better and more detailed questions to be asked at the first contact has assisted with the identification of women with cognitive impairments. Awareness that a woman has a cognitive impairment alerts PAS staff and social workers to present information more simply, and to frequently check for the woman's understanding and her capacity to carry out tasks. A clinical guideline, and education and resources have been developed to support counselling and assessment of women with cognitive impairments. Improvements to the system for collecting data since the audit will result in better informed future research.

Women with cognitive impairments are a marginalised and vulnerable group, whose reproductive health needs are not adequately recognised or addressed in current systems. While more research in this area is needed, the findings of this audit indicate there are significant differences in outcomes for women with cognitive impairments with unplanned or unwanted pregnancy compared with other women. Women with cognitive impairments have the same right to information, support, and pregnancy choices as other women in the community, but this audit indicates there are many unaddressed barriers preventing them from knowing and exercising their rights.

Acknowledgements

This project was funded by the Royal Women's Hospital and supported by the Pregnancy Advisory Service and the Women's Social Support Services. Many thanks to the managers of PAS and WSSS and to PAS staff for their support and assistance. Thanks also to Professor Christine Bigby for her valuable feedback through the writing of this article.

References

Attard, M. (1988). Mentally handicapped parents – Some issues to consider in relation to pregnancy. *The British Journal of Mental Subnormality, XXXIV*, part 1 (No. 66), 3–9.

Bayly, C. (2005). Informing the abortion debate. *O & G, Royal Australian & New College of Obstetrics & Gynaecology, 7* (1), 50–51.

Beckmann, K., Hiller, J., & Jones, D. (1996). *Factors Influencing the Timing of Abortions in South Australia*. Adelaide: Dept Community Medicine, University of Adelaide The Pregnancy Advisory Centre.

Bigby, C., & Ozanne, E. (2001). Shifts in the model of service delivery in intellectual disability in Victoria. *Journal of Intellectual & Developmental Disability, 26*, 177–190.

Booth, T. (2003). Parents with learning difficulties and the stolen generation. *Journal of Learning Disabilities, 7*, 203–209.

Brady, S. (2001). Sterilization of girls and women with intellectual disabilities: past and present justifications. *Violence Against Women*, *7*, 432–461.

Brady, S., Britton, J., & Grover, S. (2001). *The Sterilisation of Girls and Young Women in Australia: issues and progress*. Retrieved February 2, 2009, from http://www.hreoc.gov.au/disability_rights/sterilisation/

Burgen, B. (2007). Still not accepted: When women with intellectual disabilities choose to become mothers. *Women Against Violence*, *19*, 54–61.

Cheng, M., & Udry, J. (2003). How much do mentally disabled adolescents know about sex and birth control? *Adolescent & Family Health*, *3*, 28–38.

Cheng, M., & Udry, J. (2005). Sexual experiences of adolescents with low cognitive abilities in the US. *Journal of Developmental and Physical Disabilities*, *17*, 155–172.

Disability Act. (2006). *Disability Act 2006*, Act No 23/2006, Parliament of Victoria.

Ditchfield, H., & Burns, I. (2004). Understanding our bodies, understanding ourselves: The menstrual cycle, mental health and Women with learning disabilities. *Tizard Learning Disability Review*, *9* (4), 24–32.

Elkins, T., Kope, S., Ghaziuddin, M., Sorg, C., & Quint, E. (1997). Integration of a sexuality counselling service into a reproductive health program for persons with mental retardation. *Journal of Adolescent Gynecology*, *10*, 24–27.

Evans, A. (2001). The influence of significant others on Australian teenagers' decisions about pregnancy resolution. *Family Planning Perspectives*, *33*, 224–230.

Galea, J., Butler, J., Iacono, T., & Leighton, D. (2004). The assessment of sexual knowledge in people with intellectual disability. *Journal of Intellectual & Developmental Disability*, *29*, 350–365.

Harrison, S., & Berry, L. (2006). Valuing people: Health visiting and people with learning disabilities. *Community Practioner*, *79* (2), 56–59.

Innes, G. (2007). *The UN Convention, the rights of people with disabilities and domestic violence*. Retrieved July 18, 2008, from http://www.hreoc.gov.au/disability_rights/speeches/2007/violence.htm

International Association for the Scientific Study of Intellectual Disabilities (IASSID) Special Interest Group (SIRG). (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.

Jenkins, R., & Davies, R. (2006). Neglect of people with intellectual disabilities. *Journal of Intellectual Disability*, *10*, 35–45.

Kallianes, V., & Rubenfeld, P. (1997). Disabled Women and Reproductive Rights. *Disability & Society*, *12*, 203–221.

Marie Stopes International. (2006). *Unplanned pregnancy a reality for over 50% of Australian women*. Retrieved July 30, 2008, from http://www.mariestopes.com.au/news1/media_releases/unplanned_pregnancy_a_reality_for_over_50_of_australian_women/

McCabe, M., & Cummins, R. (1996). The sexual knowledge, experience, feelings and needs of people with mild intellectual disability. *Education and Training in Mental Retardation and Developmental Disabilities*, *31*, 13–21.

McCarthy, M. (1998). Whose body is it anyway? Pressures and control for women with learning disabilities. *Disability & Society*, *13*, 557–574.

McCarthy, M. (2002). Responses to Women with Learning Disabilities as they go through the menopause. *Tizard Learning Disability Review*, *7* (1), 4–12.

McCarthy, M. (2009). Contraception and women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *22*, 363–369.

McConnell, D., & Llewellyn, G. (2002). Stereotypes, parents with intellectual disability and child protection. *Journal of Social Welfare and Family Law*, *24*, 297–317.

McConnell, D., Mayes, R., & Llewelyn, G. (2008). Pre-partum distress in women with intellectual disabilities. *Journal of Intellectual & Developmental Disability*, *3*, 177–183.

Murphy, J. (2006). Perceptions of communication between people with communication disability and general practice staff. *Health Expectations*, *9*, 49–59.

Phillips, J., & Park, M. (2004). *Measuring domestic violence and sexual assault against women: a review of the literature and statistics*. Retrieved July 18, 2009, from http://www.aph.gov.au/library/intguide/SP/ViolenceAgainstWomen.htm

Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, *12*, 48–56.

Servais, L., Jacques, D., Leach, R., Conod, L., Hoyois, P., Dan., & Roussaux, J. (2002). Contraception of women with intellectual disability: prevalence and determinants. *Journal of Intellectual Disability Research*, *46*, 108–119.

Tarleton, B., Ward, L., & Howarth, J. (2006). *Finding the right support? A review of issues and positive practices in supporting parents with learning difficulties and their children*. London: Baring Foundation.

Victorian Auditor General. (2000). *Services for People with an Intellectual Disability* (Audit). Victoria: Victorian Auditor General's Office.

Walsh, D. (2008). The hidden experience of violence during pregnancy: A study of 400 pregnant Australian women. *Australian Journal of Primary Health*, *14*, 97–105.