Relationships and adults with an intellectual disability

Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability

**Brigit Mirfin-Veitch, BA (Hons)
Donald Beasley Institute**

June 2003

CONTENTS

ADULT RELATIONSHIPS

Introduction

This review provides an overview of the range of relationships that are experienced by adults with an intellectual disability. The review approaches this issue from the perspective of how such specific relationships impact, or have the potential to impact, on the lives of adults with an intellectual disability. While the information included in the review relates to families, staff and friends, the emphasis of the review is on adults' experiences of the range of relationships that they participate in.

Relationships factor strongly in the lives of all people, including adults with an intellectual disability. The volume of literature available to explore the range of relationships covered within this review is considerable. For this reason we have chosen to include the most recent literature pertaining to each relationship area.

The literature selected for inclusion in this review needs further explanation. Two types of literature predominate in the review. Firstly, in order to include the voices of adults with an intellectual disability we have utilised personal accounts written by adults, and which reflect adults' views and experiences. Second, research that has utilised qualitative methodologies is reported most frequently throughout this review. This is due to the topic area explored – the often highly personal and intangible nature of relationships has encouraged many researchers to employ qualitative methods to conduct their investigations.

The review comprises four sections. Section one discusses the role and impact of family relationships in the lives of adults who have an intellectual disability. Section two provides information relating to friendship and has a particular focus on how adults with an intellectual disability can be supported to develop friendships. Section three extends the exploration of friendship into the area of sexual and intimate relationships. Section four contributes information relating to the experiences of adults with an intellectual disability who are parents.

Due to the size and scope of this review, we have chosen to organise the review into individual sections. Although each of the sections relates to the overall topic of adult relationships, each section has been compiled separately. Each section includes a plain language summary and introduction. References are included at the end of each section.

PLAIN LANGUAGE SUMMARY

Family relationships

Despite whether adults with an intellectual disability live at home, or whether they use disability support services, their families are usually a big part of their lives. Because adults with an intellectual disability often find it difficult to make friends with other people the relationships that they have with their families are very important.

Families often make decisions which affect the lives of adults with an intellectual disability. Families make decisions about: where adults with an intellectual disability live; who supports them; who they have relationships with; how they spend their spare time; and where they work. The amount of independence people have in their lives often depends on their families' views and attitudes. Adults with an intellectual disability have different views about the role of family in their lives. Some adults value the support they receive from their families very highly, while other adults find that families try to limit their independence too much.

Most adults who have an intellectual disability live at home with their families. Researchers often study family relationships from the perspective of parents. Parents can experience quite a lot of stress and pressure when they care for their family member with a disability at home. Sometimes they lose contact with friends because they spend so much time supporting their family member. It is also common for families to be worried about the safety of their family member with a disability. This can mean that adults are not allowed any independence. Some families may also seek to have legal control over the lives of adults with an intellectual disability.

Research has shown that when people with an intellectual disability become adults, families feel that it is difficult to deal with all the changes that take place in the adults' lives. The problems for elderly parents who care for their sons and daughters with an intellectual disability have also been talked about. Older parents need help to make sure plans are in place if they can no longer care for their son or daughter with an intellectual disability. Sometimes adults with an intellectual disability also care for their elderly parents and this help needs to be recognised. Finally, brothers and sisters are often an important source of support to adults with an intellectual disability.

Adults with an intellectual disability often learn about their disability from their family. How their family talks about their disability can affect how adults feel about themselves. Sometimes families feel it is hard to talk about intellectual disability.

Families are sometimes involved in running intellectual disability services. Some adults with an intellectual disability have said that this can make it hard for them to complain about their services. Families can also have a big impact on self advocacy. If adults are supported to be self advocates by their families they will usually gain a great deal more independence than if families are against self advocacy.

This review has shown that:

- adults with an intellectual disability need to be listened to as individuals with their own views and opinions
- not all adults have a good relationship with their families, or can rely on them for support
- families sometimes find it hard to cope with caring for their family member with a disability
- older parents of adults with an intellectual disability sometimes need extra help
- brothers and sisters often provide important support to adults with an intellectual disability
- families who have legal authority over the lives of adults with an intellectual disability must make sure they encourage the adults to have as much control over their own lives as possible

FAMILY RELATIONSHIPS FOR ADULTS WITH AN INTELLECTUAL DISABILITY

Introduction

This first section of the review of adult relationships addresses the question "what do we know about the relationships between adults with an intellectual disability and their parents, and siblings?"

Despite whether adults with an intellectual disability live at home, or whether they utilise disability support services, families usually play a significant role in their lives. The relationships that adults with an intellectual disability have with their families often represent the most stable and consistent social relationships that they may experience. Reduced social networks, and limited social relationships and friendships (see later in this review) are often a feature of the lives of adults with an intellectual disability. Depending on the attitudes and values that they hold, families can either increase, or limit, the opportunities that such adults have to develop relationships with other people.

It is also widely acknowledged that families play an active role in making decisions which affect the lives of adults. Men and women with an intellectual disability often continue to seek decision making support from their families into adulthood. It is also common for adults with an intellectual disability to accept families input, or feel unable to prevent) their families from making decisions without considering their views on specific issues. Families influence, or make decisions about: where adults live; who supports them; with whom they develop relationships; how they spend their leisure time; and where they work. This makes it important to examine the relationships that exist between adults and their families. The nature of these relationships have critical influence over the level of independence and quality of life adults with an intellectual disability are able to achieve.

This section of the review on adult relationships will focus specifically on how **adults** with an intellectual disability experience interpret and/or value the role of family in their lives. It will also consider issues critical to parents and siblings who are involved in supporting adults with an intellectual disability.

Adults with an intellectual disability and their relationships with parents and siblings

Relationships with parents

This review will begin by exploring the range of attitudes that adults with an intellectual disability have expressed when considering the role of family in their lives.

Tamara Kainova (2000) described how she perceived her family.

I think that our family story is like a film about life. I'll tell you about my sister Tatjana our good parents and myself. We've got excellent parents they help us and take care of us (p 29).

Avis Hunter (1997) who was institutionalised at the age of four and who spent over 50 years living in a range of institutions in New Zealand reflected on the role and importance of family. As well as articulating what it meant to her to find and meet her family, she also identified what she believed she had "missed out on" as a result of not being involved with her family.

In 1996 I finally found my family. My family are good card players and good tellers of jokes. I know this about them now. I like them coming to visit me and I want them to keep coming… If I'd stayed with my family my life would have been different. They would have looked after me properly. They would have talked to me and I would have had my own room (p 26).

In contrast to these positive depictions of the relationships between adults with an intellectual disability and their families, some adults are increasingly voicing their dissatisfaction with the control and decision making power that their families (and particularly their parents) have in their lives.

Simone Aspis (2000) contributed to a recent book involving women with an intellectual disability telling their stories. In the process of describing her experiences of segregation and lack of basic human rights Aspis asked the following question:

Why are parents so involved in decisions about their children? I had parents of their children asking my parents if I would be willing to go out with them, why friendships were broken down and would I go on holiday. I even know one parent who had asked my parents if I would want to share a flat with their disabled youngster! Why on earth do parents still think they can make decisions about their [adult] child's life? (p 84)

Aspis' statement illustrates a common occurrence in the lives of adults with an intellectual disability – an implied assumption that parents and their adult children with an intellectual disability share the same views on all issues affecting their lives.

Another contributor to the aforementioned book described her very negative feelings toward her family. "Alice" included several messages for other adults with an intellectual disability and their families. "Alice" provided the following advice to other women with an intellectual disability:

If your parents is not doing the right things you don't have to take it as it is. It's up to you in your life. You have got a choice. You need to choose what you think is best for yourself (p 127).

"Alice" advised parents in this way:

Your parents must take the rights in letting disability members get their point of view. They are not a stupid person to what you think they are, just because you

don't hear a person do something, doesn't mean anything. They still got a brain in the same way (p 127-8).

The adults' views of the importance and role of family presented here begin to highlight some of the issues and differences that are apparent when considering this fundamental relationship. Some adults clearly value their families highly and rely on them for both practical and emotional support. Other adults with an intellectual disability resent what they see as the intrusion of their family's attitudes, values, and decision making into many different facets of their lives. This review will highlight some of the differences that are apparent between some adults with an intellectual disability and their parents and will consider how support services can respond to such differences.

Relationships with siblings

Siblings of adults with an intellectual disability have gained increasing research attention over the past decade. This increased attention can be attributed to two factors. First, there is recognition that as adults with an intellectual disability experience a greater life expectancy they will increasingly outlive their parents. Understanding the perspectives of adult siblings as potential future caregivers or support and describing their current roles in the lives of their brother or sister with an intellectual disability is an important agenda for future policy development (Griffiths and Unger 1994; Stoneman and Berman 1993). Secondly, a focus on siblings is the obvious outcome of the recognition that families (not just parents) play a central role in the lives of adults with an intellectual disability.

In a longitudinal study of aging families Krauss et al (1996) explored a variety of aspects of sibling relationships and expectations regarding future care giving roles. The study found that siblings generally maintained regular and personal contact, provided emotional support, and felt knowledgeable about the needs of their brother or sister with an intellectual disability. In cases where siblings had firm plans regarding the future care of their brother or sister with an intellectual disability 36 percent intended to reside with their brother or sister when parents could no longer fulfil the care giving role. The study also identified several factors that differentiated those siblings who were intending to provide long-term care for their brother or sister, and those who were planning to obtain residential care within the community based system. These factors were: gender - sisters were more inclined to be planning to co-reside with sisters with an intellectual disability; level of intellectual disability - co-residence was more likely when the adult with a disability had lower support needs; and current frequency of shared activity – if siblings enjoyed a high level of contact and shared activity they were more likely to be planning to co-reside in the future.

Orsmond and Seltzer (2000) furthered the exploration of the gendered nature of sibling relationships in a recent study. The focus of the study was on the differences and similarities in how adult brothers and sisters negotiate sibling roles, relationships, and future care giving expectations. Key findings of the study included: sisters provided more care and companionship for their sibling with an intellectual disability than brothers; brothers of brothers with an intellectual disability had the most positive feelings about their siblings, but they had the fewest worries about future care. Brothers of sisters with an intellectual disability showed the opposite pattern. Orsmond and Seltzer interpreted this finding as having implications for women with an intellectual disability who may be

at risk of reduced support if their most involved sibling is a brother. They also contended that there is a need for disability support services to recognise that future family involvement in services will inevitably involve siblings and attention needs to be paid to considering the needs of adult siblings in care giving or decision making roles.

Siblings may also become welfare guardians of adults with an intellectual disability. The New Zealand study (Bray et al 2000) found that while the majority of welfare guardians were parents (75%), 18 percent were siblings. The same problems previously outlined, particularly excessive control can occur with siblings who are welfare guardians.

Jacqueline Irving (1994) provides a different perspective on this specific sibling relationship. Irving tells her story of having an older brother with a disability. Irving is twenty-one years younger than her brother. While she loves her brother and feels proud of what he has achieved in his life, she holds a very negative view of the impact of his disability within her family. In particular she highlights the enormous physical and emotional pressures that were placed on her parents, firstly as they struggled to care for him at home, and then after he had been institutionalised (against their wishes). She also talked of the bitterness and resentment that her older sisters had toward their brother whom they perceived as taking up all of the family's emotional and financial resources. Even as adults, her three sisters refused to have any kind of relationship with their brother with a disability for this reason.

Irving's personal story provides a contrast to many sibling accounts and/or sibling research which frequently have identified the positive aspects of this specific family relationship. Siblings have been reported in the literature as perceiving their disabled sibling as enhancing their lives. Irving's experience of disability has had such an impact that she chooses to deny her own disability to avoid experiencing (what she perceives to be) inevitable, negative consequences on her life.

While most sibling research approaches this topic from the perspective of the non-disabled sibling(s) Davies and Jenkins (1997) provide an insight to the way adults view such relationships. In a study of self identity Davies and Jenkins identified that young adults with an intellectual disability can sometimes feel intense frustration when their siblings attain goals that are important but seemingly unreachable for them.

Families' relationships with adults with an intellectual disability

A range of research has been selected and summarised below as research which illustrates the range of issues that have been identified in relation to families' perceptions of adults with an intellectual disability. However, because the primary focus of this review is on **adults** (rather than families) attention has been paid to highlighting family relationship issues in terms of the degree to which they have the potential to impact on the lives of adults with an intellectual disability.

Researchers who have explored the relationship between disability and family have commonly approached this issue from the perspective of parents (and to a lesser degree) siblings. Many studies have examined families that include a child or adult with an intellectual disability with the aim of exploring the "quality of life for families".

Cummins and Baxter (1997) considered quality of life issues within families who care for a member with an intellectual disability. The authors contended that the deinstitutionalisation movement has had major consequences for families and that families who have had family members returned to the community have rarely been adequately informed of such transitions. They also argue that the removal of the option of residential placement in institutional style facilities has resulted in more families caring for their disabled family member for longer. Cummins and Baxter contend that families who care for a disabled member experience considerable pressure in doing so and stated:

> *The reported influences of family well-being, caused by care-giving for a disabled family member are, unfortunately, overwhelmingly negative (p 4).*

Research in this area has strongly indicated that families that include a member with a disability frequently experience reduced social networks and are, therefore, more dependent on formal service provision for support. Cummins and Baxter also suggest that the special skills needed to provide support to families have been a neglected area of professional training.

However the view that deinstitutionalisation is responsible for the large numbers of families who care for their relatives at home can be challenged.
Research has confirmed that historically adults with an intellectual disability have more commonly been cared for at home rather than in institutional or community based disability support services. When commenting on the lifelong impact of care giving within the American content Heller (1998) said:

> *Families of adults with mental retardation are their primary providers of care, with at least 80% of all ages with mental retardation living at home. Many of these adults are not known to the developmental disabilities service system: estimates indicate that as many as 40% fall into this category (p 21).*

Furthermore, Fujiura (1998) contended that:

> *We know the least demographically about what is certainly the largest population: those supported at home by their immediate families, other relatives or benefactors (p 225).*

It is for this reason that Fujiura believes that families represent the key constituency in disability policy. Acknowledgement of the fact that most adults with an intellectual disability are cared for within the context of their families has also given rise to concern about whether the current American disability support services structure will be able to cope as older parents die or become incapacitated. The role of adult siblings as care providers is also beginning to be explored as a response to this concern.

Research which is concerned with the notion of family and disability currently tends to approach this issue by exploring both the rewards associated with care giving, and the stresses or pressures this activity can present (Grant et al 1998; Walmsley 1993). In the New Zealand context, research attention has been paid to the issue of gender with the role of mothers as primary caregivers being investigated (Munford 1991; Sonntag 1991).

Todd and Shearn (1996), and Shearn and Todd (1997) have specifically focused on the experiences of parent caregivers during their offspring's adult years. This research utilised qualitative interviews as the primary method of data collection. Shearn and Todd (1997) analysed the types of activities that parents of adults with an intellectual disability were involved in as being:

- body work (physical tasks associated with care giving)
- safety work (minimising or preventing "risk" in the lives of the adults)
- development work (encouraging the acquisition of new skills)
- social and recreational work (finding activities to involve and engage their adult child)
- service work (ensuring that services met both the needs of themselves and their adult child)
- identity work (dealing with the issues involved either informing or denying their child information about their disability)
- articulation work (coordinating the range of services or activities necessary to support their adult child).

This study raises issues associated with families caring for their children with an intellectual disability into adulthood. At a time when parents are often withdrawing from taking an active role in their children's lives, parents of adults with an intellectual disability are often facing a whole new set of parenting issues and are required to respond to this new phase in their disabled child's life. Shearn and Todd (1997) argue that these issues need to be taken into consideration by family support services and that attention must be paid to individual family circumstances in order for real benefits to parents and to adults themselves being made.

Adults with an intellectual disability often lead lives that are determined or dominated by others. Families of such adults often have to deal with extreme ambivalence relating to the degree of independence that their family member wants to achieve, and their own concerns about the danger that such independence might present for that person. Heyman and Huckle (1993) conducted a qualitative study which explored the notion of hazards in the lives of adults with an intellectual disability. The study examined adult and family carer perspectives of the hazards associated with everyday life for adults with a moderate intellectual disability. Heyman and Huckle defined the term hazard as being used to describe the *"perceived possibility of adverse consequences arising from an action"* (p 143). Hazards may be viewed as either risks or dangers. The study found that individual families view hazards in different ways, and that within families it is common for adults and their family carers to view this issue differently.

Adult and family carer attitudes towards hazards were considered in combination and were classified on two dimensions, the extent to which hazards were treated as risks and not dangers and the extent to which adults and family carers agreed in their approach to hazards. Using these dimensions families (adult and family carer combinations) were categorised into three types that illustrated family approaches to hazards. These were labelled: shared danger avoidance; conflict; and shared risk taking.

Shared danger avoidance referred to the situation where adults and family carers viewed hazards as dangers to be avoided. Using public transport, walking alone, going out with friends, having an intimate relationship with another person, getting a job,

getting married, or living independently were all viewed by the adults and family carers in this group as too dangerous. Adult views complemented but were heavily influenced by those of their family carer. The result of this shared view of hazard was that the adults had limited opportunities to develop social relationships and they were encouraged to have a high level of dependence on their family carer who usually held a pessimistic view of the adult's abilities.

The concept of **conflict** described family situations where adults and their family carers had opposing views in their approach to hazards. Family carers viewed hazards as dangers to be avoided while the adults tended to accept certain risks in order to achieve greater autonomy. As a result of these conflicting views family carers frequently viewed the adult as rebellious while the adults tended to see the carer as needlessly restrictive. These relationships were characterised by mutual incomprehension and interpersonal conflict.

The third category was termed **shared risk-taking**. Adults and family carers who were identified as belonging to this category both accepted adult risk taking in a limited range of areas. Family carers carefully assessed the risk associated with hazards and balanced the need to protect the adult against the potential risk taking activity. Adults in this category had increased social networks and enhanced opportunities. However, they were inevitably exposed to greater hazards (with potentially negative consequences) which created a higher level of anxiety for their family carers.

This study highlights the difficulties that some adults with an intellectual disability experienced during their attempts to achieve greater personal autonomy. It also serves to illustrate the tensions and conflicts for families as they endeavour to support adults' attempts to achieve more independence. Finally, the study identifies the powerful influence that families can exert over the many facets of adults' lives.

Families may also seek legal authorisation for controlling the lives of adults with an intellectual disability. In New Zealand, the Protection of Personal and Property Rights Act 1988, allows the Court to appoint welfare guardians for people who are "wholly unable to make or communicate decisions" in specific areas of their lives. Research undertaken into the case law and actual implementation of this Act (Bray et al 2000) shows that this provision is often used inappropriately and in ways that contradict the primary objectives and provisions in the Act. Too often, parents and siblings are appointed as welfare guardians for people who do not meet the strict jurisdictional criteria. Furthermore, the reasons for their applications are frequently to prevent the person moving out of institutional care, or to limit the person's opportunities for development and self-determination (Bray 1996).

Transition into adulthood

Another area that has been identified as presenting significant parental stress is the period of transition into adulthood. In a study conducted by Mellon, Wilgosh, McDonald and Baine (1993) parents of young adults participated in qualitative interviews in order to identify the types of stresses experienced by families of young adults with severe disabilities during the transition to adulthood. Six themes emerged from the qualitative analysis of the interview data. These themes related to: uncertainty about the future;

transition in services and lack of services or options, advocacy, physical maturity, and individual vulnerability. Mellon et al contend that understanding parental concerns and needs is integral to providing effective support and services to families of young adults with severe disabilities. Families will accept and support moves toward greater independence for their (young adult) children with severe disabilities if they are satisfied that service infrastructures are adequate to meet their diverse and significant needs.

Older adults who live with their parents

In a recent article Braddock (1999) provided a commentary on the demographic and policy issues affecting American families. Braddock stated:

> *As the lifespan of persons with developmental disabilities increases, they require long-term care for longer periods of time (p 158).*

In the American context the likelihood of older people with an intellectual disability living into their retirement and outliving their family caregivers has increased significantly. Furthermore, this situation has created a growing need for more services and supports. Braddock contended that older parents who provide care at home for their adult sons and daughters are at risk of increased pressures related to providing care for longer.

Heller and Factor (1993) examined the determinants of older parents' care giving burden and desire for residential placement of their adult child. Interviews were conducted with sixty-two parents and were analysed using statistical analysis programme SPSS. The study showed that support resources play a significant role in reducing the perceived care giving burden of older parents. Unmet service needs were reported in order of frequency and included: residential program information; out of home respite care; recreation activities (for adult); in home respite care; guardianship information; case management; specialised therapy; support groups; and information on financial planning. Heller and Factor contend that these results indicate a strong need for permanency planning relating to older parent caregivers and their adult sons and daughters with an intellectual disability in order to reduce problems when older parents can no longer continue to provide care.

Planning for those adults who remain at home with their parents until mid-life and who at some time need to experience a transition from parental care into alternative disability support services has been the subject of Australian research. Bigby (1996) contends that research has shown that parents are reluctant to plan for their adult child's future care and that there is little evidence regarding the efficacy of such planning if it does occur. Bigby conducted a study which addressed these issues by retrospectively examining the nature and implementation of plans made by parents of older adults with an intellectual disability.

The study found that most parents had undertaken some form of planning relating to the care of their adult child with an intellectual disability which was intended to be implemented when parents had died, were incapacitated, or chose to cease being the primary care-giver. Four types of plans were identified: implicit key person succession plans; explicit key person succession plans; financial plans; and residential plans. Key person succession plans referred to the explicit agreements or implicit understandings that

parents had negotiated with others about their future role in the life of the adult with an intellectual disability. Most of the key people nominated in these plans were siblings (88%). Residential plans involved arranging alternative residential accommodation and support for the person with a disability. Financial plans (which were usually implemented in conjunction with another sort of plan) referred to a process by which the adult with an intellectual disability would have access to financial resources in the future.

Bigby contended that parents who had had involvement in specialist disability day services were more likely to have made plans regarding the future care of their relative than other parents. If parents did not have an obvious successor it was less likely that they had made plans. Another interesting finding of this study was that succession plans were implemented overwhelmingly due to reasons of parental death or incapacity suggesting that most parents who cared for their sons and daughters into mid-life realised their ambition to care for as long as they were able.

The findings of this study suggest that a social network approach towards planning assistance is appropriate for elderly parents. Such an approach would broaden the focus of intervention from parents and close friends and involve members of the person's broader informal support network in planning. This would bring obvious benefits to the person with an intellectual disability particularly when a transition is made during mid-life. Findings of a study by Hayden and Heller (1997) are also relevant to mention in relation to this issue. Support, problem solving and coping ability, and personal burden of older and younger parents of adults with an intellectual disability were explored. The study found that older caregivers experienced considerably less personal burden than younger caregivers, but were less likely to seek outside help from the disability support service system. This finding has implications for adults with an intellectual disability who may be disadvantaged through their lack of access to alternative forms of support.

Adults with an intellectual disability as care providers

Attention has also been paid in research to the situation where adults with an intellectual disability themselves fulfil necessary support roles within their family. Barette (2000) described her experience of caring for her mother when her father died:

> *I lived with my mum after dad died. That's why I left the Centre, look after my mum, she taken ill, I got sent home with her. Mum drinking a lot. When me dad died she drinks more. My mum keep on drinking, stop her thinking of him. I did everything. Washed her. Dressed her. She couldn't feed herself and I fed her. I coped, yeah. My cousin couldn't believe her eyes, what I did for mum. I coped (p 207-8).*

Despite the significant care that Barette provided for her mother (including managing medications and consulting doctors) she received no counselling after her mother's death. A decision was made by another family member that she should not return to live in the family home and it was arranged that she should live in a group home.

Heller et al (1997) conducted a study which was designed to determine whether support provided to caregivers by their adult children with an intellectual disability would influence their care giving appraisals. This unique study demonstrated that support to

parent caregivers by adults with an intellectual disability resulted in parents perceiving their care giving role more positively. This study highlights the importance of understanding reciprocal care giving roles and that adults with an intellectual disability can be effective support providers (the issue of reciprocity is also addressed in the next section of this review – Adults with an intellectual disability and friendship).

Respite care

Another important service area for families is that of respite care. Cotterill et al (1997) challenge the traditional notion of the purpose of respite. Respite is generally understood to mean the provision of a break for carers and relief from their caring responsibilities. It has also been argued that respite plays a role in delaying the move from home into long-term care for children and adults with an intellectual disability. Cotterill et al however contend that the aims of respite are coming under increasing scrutiny and are now being framed around the needs and wishes of people with an intellectual disability themselves. This group of researchers argue that respite can and should provide positive opportunities for people with an intellectual disability in terms of increased independence, a widened range of activities, improved quality of life and greater social integration.

Flynn et al (1994, 1996) conducted innovative research with people with an intellectual disability themselves in order to understand their experiences of respite services and their views on how such services could be improved. The research identified nine key principles which relate to the delivery of respite services. People with an intellectual disability said respite services should:

- enable people to have control over when and where they go
- who they are with, what they eat, what they spend their money on and when they go out
- offer good experiences and personal advantages in terms of being with friends, being treated like an adult and feeling safe
- sustain feelings of personal worth and esteem
- be ordinary and separate from accommodation offered to people on a long term basis
- promote individual supports as a result of individual planning rather than group care which leans toward meeting minimal needs
- sustain people's significant relationships and make links with their lives and particularly their diverse roles in families
- be local, even in emergencies
- be responsive to the ideas and needs of service users
- part company with the dispiriting features associated with unit-based respite (p 783).

Freedman et al (1999) examined the use of respite services by aging families of adults with an intellectual disability. This study which was conducted over four and a half years, identified that respite use was predicted by three characteristics: poorer functional abilities; better health in the adult with an intellectual disability; and greater maternal care-giving burden. Families displayed hesitancy to access increasingly available services which the researchers contributed to their tradition of self reliance. The finding that respite recipients were more likely to be adults in better health is the one with most

relevance to this group. Being in reasonably good health was suggested by the researchers as possibly constituting a minimum threshold for such adults to receive care.

> *Although respite is reaching increasing numbers of families, our findings indicate a gap in delivery of respite services to families in which the adult with mental retardation is in poor health.*

Respite services which meet the complex needs of adults with an intellectual disability and their aging families are necessary to ensure the well-being of both groups of people.

The role of family in adults' understandings of intellectual disability

Davies and Jenkins (1997) conducted a study which explored the self-identities constructed by adults with an intellectual disability. The study sought to determine whether people with an intellectual disability "understand" what is meant by that label and whether they applied such a label to themselves. Parents provided data for the study, along with young adults with an intellectual disability. Analysis of the interviews with young adults suggested that they did not have access to the cultural discourse about them – that is they did not understand the various terms and meanings frequently used to describe themselves and others with an intellectual disability. It was found that such young adults were usually dependent on their parents (and in most cases their mothers) for their understanding of the various labels used about them in relation to their intellectual disability. Despite this reliance parents were found to avoid discussing the meaning of intellectual disability with their sons and daughters. Some parents reported feeling it would be too cruel to make their (adult) children aware of this fact about themselves, while others assumed that their (adult) children would not be able to understand.

Analysis of the interviews held with the young adults themselves highlighted a contrast between parents' views and the actual knowledge held by the young adults about their own disabilities. They found that when parents had explained the fact of their son or daughter's disability to them, that person could repeat the explanation with considerable accuracy. When parents had given limited or partial explanations (aimed to "protect" the individual) the young adults seemed to hold rather unique or idiosyncratic notions about themselves. Despite this, the young adults who participated in this study were clearly aware of the implications that intellectual disability had on their ability to achieve aims and goals usually associated with adulthood (eg, gaining a driver's license, getting a 'good' job, getting married, having a baby). Davies and Jenkins contend that inadequate understandings of the nature of their intellectual disability can further emphasise the disempowerment that adults with an intellectual disability experience frequently in their everyday social interactions.

In a study focused on the development of primary health care for young adults with an intellectual disability (Gillman et al 2000) the perspectives of young adults, family carers and professionals were sought. Within focus groups the issues of diagnosis and labelling were raised by participants in the family carer and young adult groups. The study found that family carers were very aware of the stigmatising effects of labelling individuals. Family carers, therefore, often sought a (perceived) less stigmatising label than that of learning difficulty (intellectual disability). For example labelling a person with a sensory

or physical disability was preferable to using the learning difficulty (intellectual disability) label. The researchers analysed this behaviour as indicating that:

> *…a diagnosis of learning difficulty is perceived by many family carers to embrace the whole person and shape their identity* (p 395).

Research by Todd and Shearn (1997) is consistent with the work of Gillman et al in a paper describing the role that parents play in providing knowledge of intellectual disability to their adult offspring with such labels it was found that while parents recognised and dealt with the stigma of intellectual disability within their own lives, they had actively tried to prevent their adult offspring having to deal with similar difficulties. Todd and Shearn identified a number of consequences arising from this parental strategy of shielding their adult sons and daughters from knowledge relating to their identities. For example, hiding or denying the label intellectual disability continues to legitimate the stigma associated with it. Furthermore, if people with an intellectual disability are unaware that the world in which they live rejects and discriminates against them, they are unable to present a challenge to that world. Todd and Shearn conclude that:

> *…learning disability is not so much rendered socially invisible but that it is hidden from people themselves. That is, many people with learning disabilities may be invisible to themselves (p 363).*

The role of family in the area of sexual and intimate relationships

The area of sexual and intimate relationships is another aspect of the lives of adults with an intellectual disability in which parents play an important role. Parents can be very influential in determining whether such adults have access to the knowledge and opportunities necessary for the initiation and maintenance of sexual and intimate relationships. Research information relating to this area is significant and sexual and intimate relationships will comprise the fourth section of this review of adult relationships.

The role of family in adult services

Even when adults with an intellectual disability do not live at home with their families, families (and particularly parents) still play a significant role in such adults lives. Families rather than adults with an intellectual disability themselves, are commonly treated as "the consumer" of disability services. One such example of this in the New Zealand context can be seen during the process of deinstitutionalisation. Families have a tremendous influence over how, when (and even if) such initiatives will occur. It is typically parents and families who make decisions regarding when an individual will make a transition from an institutional facility into an alternative community based facility. In New Zealand this control has been exacerbated by the large scale appointments of welfare guardians for people living in institutions, sought for the purpose of preventing community living (Bray 1996; Bray et al 2000). Furthermore, it is only very infrequently that adults with an intellectual disability are given the opportunity to choose the new service to which they are making the transition.

Contrary to this disempowering influence on an initiative designed to increase the quality of life for adults with an intellectual disability, families can also play a vital role in ensuring the success of transition from an institutional to a community based disability service. New Zealand research has illustrated the critical role that families can play in ensuring that adults with an intellectual disability are well supported during major changes in service delivery (Mirfin-Veitch et al 1998, 2000). Research has indicated that parents and siblings have an increased involvement in the new disability support system directly following the transition of their relative (Mirfin-Veitch et al 2000; Seltzer et al 2001). Major changes in service delivery such as deinstitutionalisation also have the potential to encourage renewed or increased family involvement, particularly between adults with an intellectual disability and their siblings (Mirfin-Veitch et al 2000; Seltzer et al 2001).

Given the prominence of families within disability support service structures it is important to look critically at their involvement in such structures. Aspis (1995), a woman with a learning disability herself, provides an analysis of the role of parents in the management structure of a charity providing residential support to people with an intellectual disability in the community. Aspis refers to herself as a group home survivor and highlights the conflict generated through parents' (of the individuals living in the house) also being part of the management executive. She is of the view that parents often lack objectivity especially in situations where problems occur within the service.

Aspis contends that parents' loyalty is split between the service and their adult sons and daughters and believes that some parents get anxious when their son or daughter speaks out against a service organisation. Her interpretation of this anxiousness is that parents are concerned that the person may lose their place and have to return home. Aspis also holds the view that parents want to ensure the dependency of their children is maintained despite the fact that they are living outside of the family home and are adults. She stated:

> *All the parents saw their children as disabled and therefore treated them as victims. This was reinforced by the group home's policies which created dependency and made it easier for parents to control their children's environment (p 17).*

While Aspis' comments reflect her own individual experience they do highlight the important role that parents can play in the governance of services designed to meet the needs of children and adults with an intellectual disability. As the focus of services and supports to people with an intellectual disability have developed toward a model of community inclusion and empowerment families have been forced to work together with community agencies to achieve these goals. In the context of these partnerships tensions and conflicts have arisen if differences in perspectives and/or priorities between parents and community members are not resolved. Unresolved tensions and conflicts can contribute to negative outcomes for the people that the services are intended to benefit.

Bond and Keys (2000) examined the forces that influence the quality of parent-community member relations. The results of this study suggested that when differences between parents and other individuals fulfilling a governance role are recognised and valued, board operations are likely to be more successful and focused on providing effective services. Bond and Keys identified a number of action implications for improving the relationships between parents and community members in governance

roles including: knowing the organisation's history; using the knowledge of that history to strengthen inter-group relations, recruiting and selecting diverse board members who value difference; assessing how strongly board members identify with either a parent group or a community member group; finding ways to recognise the unique contributions of each group; and ensuring clarity of roles. Kaplan (1993) also highlighted the importance of exploring and implementing ways to ensure positive parent-community collaboration in order to ensure progressive, innovative supports for adults with an intellectual disability.

Another area that families of adults take an active role in is in the area of Individual Lifestyle Planning (ILP's). Individual lifestyle planning for people with an intellectual disability in services is based on the assumption that it encourages service users with a range of abilities to make important decisions about their lives. Carnaby (1997) contended that given the experience and influence of family in the lives of service users careful consideration needs to be paid to including families in such processes in a way that recognises and responds to the culture (ethnicity, class, lifestyle) of each family.

Self advocacy and families

Self advocacy by adults with an intellectual disability is now well-established. Mitchell (1997) provided the following definition of self advocacy which identified the listed statements (provided by self advocates) as representing the meaning of self determination: speaking up for yourself; having opinions and making choices; being listened to and taken seriously; learning new skills; personal development; helping and representing others; getting information; not being treated as a child; rights and responsibilities; taking risks; influencing services; changing attitudes and labels; taking up specific issues; social contact and support; joining with other oppressed groups aiming for social change; independence; being part of the real world.

Mitchell conducted a study which had the aim of addressing the question of adulthood in general and the impact of self advocacy on families in particular. The preliminary results of Mitchell's study indicate that parents who already consider their son or daughter to be an adult may accept and encourage self advocacy. In many cases, however, parents will be challenged, either directly or indirectly, by self advocacy and may limit the extent to which their adult sons and daughters with an intellectual disability can achieve greater independence and control in their lives. This finding has important implications for the future development and application of the concepts of self advocacy and self determination.

Family responses to employment

In a study which utilised focus groups, adults with an intellectual disability explored issues related to employment. Di Terlizzi (1997) identified that such adults have few opportunities to discuss their experiences at work. For many of the adults who took part in the study, discussion relating to work only took place with disability service staff if they were experiencing problems and work was not often discussed with relatives of friends. One of the participants said: *"I used to talk about nothing else, I was excited and it got a bit too much for my parents."* The finding that adults with an intellectual

disability have reduced opportunities to systematically explore and discuss their work related interests, placement options and how they could be accessed may result in decreased opportunities for positive employment experiences.

The issue of employment and the factors which impact on the ability for adults with an intellectual disability to experience positive employment opportunities will be explored comprehensively in a later review.

Implications for support service development

This review has identified a range of issues related to adults' relationships with their families. The review has sought to discuss those issues that have the potential to impact on adults' abilities to experience positive relationships with their parents and siblings, or to achieve greater personal autonomy. A strong theme to have emerged from this review is that depending on the attitudes and values that they hold, families can either increase, or limit, the opportunities that adults with an intellectual disability have to develop relationships with other people. A number of implications for services involved in providing family support and/or intellectual disability service can be drawn from this review.

- It is vitally important that adults with an intellectual disability are consulted with and listened to as individuals with their own views and opinions.

- It cannot be assumed that adults with an intellectual disability will enjoy a positive relationship with their families, or will be able to rely on them for support. Support services must take into consideration the individual family context of each adult with an intellectual disability.

- Families of adults with an intellectual disability can experience a reduced quality of life due to the pressures and demands of providing support to their sons and daughters into adulthood. It is important that family support services have an orientation towards families who are in this position.

- Older parents who care for their adult sons and daughters often have support needs but are resistant to seeking additional support to care for their family member. For this reason it is important to make appropriate services accessible, and to create services that are responsive and which have the ability to be individualised to meet families' specific needs.

- Given the vital role of siblings in the lives of adults with an intellectual disability it is important for family- and disability support services to consider the ways in which they can support the long-term relationships between brothers and sisters with and without disabilities.

- Families have a powerful influence over the lives of adults with an intellectual disability and as a result tension often exists between adults and their families. Attention should be paid to supporting adults to negotiate issues related to them achieving a greater degree of personal autonomy in situations when their families are resistant to such changes.

- The transition into adulthood for men and women with an intellectual disability has been identified as a particularly difficult time for both families and young adults themselves. Families will accept and support moves toward greater independence for their (young adult) children if they are satisfied that service infrastructures are adequate to meet their needs.

- In order to ensure that adults with an intellectual disability are well supported in the situation where older parent caregivers are incapacitated, consideration needs to be paid to planning assistance for elderly parents.

- Adults with an intellectual disability do fulfil vital support roles within some families. Family and disability support providers must consider the impact of changing the nature of service provision within such families to avoid negative effects for either adults or the family member that they support.

- The approach to respite care provision must be oriented toward the needs of adults with an intellectual disability as well as to the needs of their family care provider.

- Families often experience difficulty and tension when considering whether or not to provide their adult sons and daughters with information relating to the fact of their intellectual disability. Families, therefore, need assistance to explore the impact of providing or denying such information. They may also need the opportunity to develop skills which enable them to impart information relating to an individual's self identity appropriately.

- Disability support services need to be aware of the tensions and difficulties that can occur when parents are involved in a governance role in such services.

- Parents and siblings are sometimes provided guardianship status by the Court under the Protection of Personal and Property Rights Act. Such "last resort" legislation should only be used when absolutely essential, and such guardians should be well-informed about their legal responsibilities. Reviews of such orders should also examine whether the guardian is encouraging or preventing the adult's development and community integration, in the light of the Act's principles and directions.

References

'Alice in Wonderland' with Walmsley J. 2000. My Life. In Atkinson D, McCarthy M, Walmsley J, Cooper M, Rolph S, Aspis S, Barette P, Coventry M, Ferris G (eds). *Good times, Bad Times: Women with learning difficulties telling their stories.* Worcestershire: BILD Publications.

Aspis S. 1995. Tales of a group home survivor. *Community Living,* January: 16-7.

Aspis S. 2000. A disabled woman with learning disabilities fights back for her rights. In Atkinson D, McCarthy M, Walmsley J, Cooper M, Rolph S, Aspis S, Barette P, Coventry M, Ferris G (eds.). *Good times, Bad Times: Women with learning difficulties telling their stories.* Worcestershire: BILD Publications.

Barette P with Walmsley J. 2000. Death and Bereavement. In Atkinson D, McCarthy M, Walmsley J, Cooper M, Rolph S, Aspis S, Barette P, Coventry M, Ferris G (eds). *Good times, Bad Times: Women with learning difficulties telling their stories.* Worcestershire: BILD Publications.

Bayley M. 1997. *What price friendship?: Encouraging the relationships of people with learning difficulties.* Minehead: Hexagon Publishing.

Bigby C. 1992. Access and linkage: Two critical issues for older people with an intellectual disability in utilising day activity and leisure services. *Australia and New Zealand Journal of Developmental Disabilities, 18* (2), 95-109.

Bigby C. 1996. Transferring responsibility: The nature and effectiveness of parental planning for the future of adults with intellectual disability who remain at home until mid-life. *Journal of Intellectual and Developmental Disability* 21(4): 295-312.

Bond M, Keys C. 2000. Strengthening parent-community member relations on agency boards: Comparative case study. *Mental Retardation* 38(5): 422-35.

Braddock D. 1999. Aging and developmental disabilities: Demographic and policy issues affecting American families. *Mental Retardation* 37(2*)*: 155-61.

Bray A. 1996. The Protection of Personal and Property Rights Act 1988: Progress for people with an intellectual disability? *Butterworths Family Law Journal* 2(3): 51-6 and 2(4): 64-6.

Bray A, Dawson J, van Winden J. 2000. *Who benefits from welfare guardianship?* Dunedin: Donald Beasley Institute.

Carnaby S. 1997. A comparative approach to evaluating individual planning for people with learning disabilities: challenging the assumptions. *Disability and Society* 12(3): 381-94.

Cotterill L, Hayes L, Flynn M, Sloper P. 1997. Reviewing respite services: some lessons from the literature. *Disability and Society* 12(5): 775-88.

Cummins R, Baxter C. 1997. The influence of disability and service delivery of quality of life within families. *International Journal of Practical Approaches to Disability* 21(3), 2-8.

Davies C, Jenkins R. 1997. 'She has different fits to me': how people with learning difficulties see themselves. *Disability and Society* 12(1): 95-109.

Di Terlizzi M. 1997. Talking about work: I used to talk about nothing else, I was excited and it got a bit too much for my parents. *Disability and Society* 12(4): 501-11.

Flynn M, Liverpool Self Advocates. 1994. *Taking a break: Liverpool's Respite services for adult citizens with learning disabilities.* Manchester, National Development Team.

Flynn M, Willoughby P, Eley R. 1996. Reviewing respite services for adults with learning disabilities. *Tizard Learning Disability Review* 1(2): 9-12.

Freedman R, Griffiths D, Krauss M, Seltzer M. 1999. Patterns of respite use by aging mothers of adults with mental retardation. *Mental Retardation* 37(2): 93-103.

Fujiura G. 1998. Demography of family households. *American Journal on Mental Retardation* 103(3): 225-35.

Gillman M, Heyman B, Swain J. 2000. What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability and Society* 15(3): 389-409.

Grant G, Ramcharan P, McGrath M, Nolan M, Keady J. 1998. Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research* 42(1): 58-71.

Griffiths D, Unger D. 1994. Views about planning for the future among parents and siblings of adults with mental retardation. *Family Relations* 43: 1-8.

Hayden M, Heller T. 1997. Support, problem-solving/coping ability and personal burden of younger and older caregivers of adults with mental retardation. *Mental Retardation* 35 (5): 364-72.

Heller T. 1998. Current trends in providing support for families of adults with Mental Retardation. *TASH Newsletter* 24(5): 21-4.

Heller T, Factor A. 1993. Aging family caregivers: Support resources and changes in burden and placement desire. *American Journal on Retardation* 98(3): 417-26.

Heller T, Miller A, Factor A. 1997. Adults with mental retardation as supports to their parents: Effects on parental care giving appraisal. *Mental Retardation* 35(5): 338-46.

Heyman B, Huckle S. 1993. 'Normal' life in a hazardous world: how adults with moderate learning difficulties and their carers cope with risks and dangers. *Disability, Handicap and Society* 8(2): 143-60.

Hunter A. 1997. *My Life*. Dunedin: Donald Beasley Institute Inc.

Irving J. 1994. Experiencing disability. *Disability and Society* 9(4): 543-7.

Kainova T with Cerna M. 2000. What life is like? In K Johnson and R Traustadottir (eds). *Women with an intellectual disability: Finding a place in the world.* London: Jessica Kingsley Publishers.

Kaplan C. 1993. Enhancing the consumer-family-staff relationship in adult services. *Mental Retardation* 31(5): 326-31.

Krauss M, Seltzer M, Gordon R, Friedman D. 1996. Binding ties: The roles of adult siblings of persons with mental retardation. *Mental Retardation* 34(2): 83-93.

Mellon S, Wilgosh L, McDonald L, Baine, D. 1993. Transition into adulthood: stresses experienced by families of young people with severe disabilities. *Developmental Disabilities Bulletin* 21(1): 34-45.

Mirfin-Veitch B, Ross N, Bray A. 2000. *Templeton Resettlement Family Experiences Project: Preliminary report- Phase One.* Dunedin: Donald Beasley Institute.

Mirfin-Veitch B, Ross N, Bray A. 1998. *Templeton Resettlement Family Experiences Project: Progress report - Phase Two.* Dunedin: Donald Beasley Institute.

Mitchell P. 1997. The impact of self –advocacy on families. *Disability and Society* 12(1): 43-56.

Munford R 1991. The experiences of women who care for people with an intellectual disability. Network 1(1): 22-7.

Orsmond G, Seltzer M. 2000. Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. *American Journal on Mental Retardation 105* (6): 486-508.

Seltzer M, Krauss M, Hong J, Orsmond G. 2001. Continuity or discontinuity of family involvement following residential transitions of adults who have mental retardation. *Mental Retardation* 39(3): 181-94.

Shearn J, Todd S. 1997. Parental work: an account of the day-to-day activities of adults with learning disabilities. *Journal of Intellectual Disability Research* 41(4): 285-301.

Sonntag E. 1991. Facing the pain of reality: stress and the caregiver. *Network* 1(1): 26-7.

Stoneman Z, Berman P. 1993. *The effects of mental retardation, disability, and illness on sibling relationships.* Baltimore: Paul Brookes Publishing Company.

Todd S, Shearn J. 1997. Family dilemmas and secrets: parents' disclosure of information to their adult offspring with learning disabilities. *Disability and Society* 12(3): 341-66.

Todd S, Shearn J. 1996. Struggles with time: the careers of parents with adult sons and daughters with learning disabilities. *Disability and Society* 11(3): 379-401.

Walmsley J. 1993. Contradictions in caring: reciprocity and interdependence. *Disability, Handicap and Society* 8(2): 129-41.

PLAIN LANGUAGE SUMMARY

Friendships

Having friends is an important part of most people's lives. While adults with an intellectual disability want friends, they often find it hard to meet people and to make friends. Friends are people who listen, and who understand. Friends make people feel like they are liked and valued by others. Friends can also support people to stand up for their rights or stand up for them.

Adults with an intellectual disability have talked about the importance of friends in their lives. They have said that without friends that they feel like they have no one in their lives. They have also said that having friends makes them feel happy with their lives. If adults with an intellectual disability do not have friends in their lives they can end up feeling lonely, physically ill, or depressed.

A lot of the research about friendships is about friendships between people with and without an intellectual disability. We need to be careful not to value friendships between people with and without disabilities more highly than friendships between disabled people. Sometimes when friendships are written about only the views of the non-disabled person are heard. This means that we do not always know what disabled people think about their friendships. Friendships between adults with an intellectual disability and the staff that work with them sometimes happen but it is important not to see all relationships between "clients and staff" as friendships. It is important, however, for staff to support adults with an intellectual disability to make friends and to be able to meet with friends.

Research says that it is sometimes hard to keep friendships going. The difficult things about making friends have been called "barriers to friendships." Some of these barriers are caused by the fact that adults with an intellectual disability do not always feel good or confident about themselves. Sometimes they do not have money or transport in order to make arrangements to meet friends. Some adults live in services that make it hard for them to meet other people, or their families prevent them from meeting others. Other barriers to friendships can be caused by attitudes such as "people with an intellectual disability do not, or cannot make friends". In some cases adults with an intellectual disability have just not had any practice in meeting people or developing friendships. Finally, for adults who cannot speak it is even more difficult to meet people and make friends.

A number of services have tried to help adults with an intellectual disability meet more people and to make friends. Sometimes adults have been linked up with another person in the community so that they can get to know one another and hopefully, develop a friendship. Self advocates have also been important in getting the community to understand that adults with an intellectual disability need friends too. Some services have tried to give adults more opportunities for meeting more people and have tried to get adults with an intellectual disability more involved in community activities.

This review has shown that:

- friendship is important in the lives of adults with an intellectual disability

- support in the area of friendships should be available to all adults with an intellectual disability who want to make friends with other people
- support should be given to people to participate in community activities and also to develop relationships in the community
- some adults with an intellectual disability will need a lot of support if they are to make friends and keep their friendships going
- adults with an intellectual disability need more than one friend.

ADULTS WITH AN INTELLECTUAL DISABILITY AND FRIENDSHIPS

Introduction

> *Friendship, and having friends, is an essential part of being human. Friends are vitally important in our lives (Staub 1998: p 3).*

People with an intellectual disability are the focus of a great deal of research investigating their quality of life and the services they use. Emerging from this work has been the acknowledgement and understanding that valued and satisfying relationships, including friendships, are critical to the quality of life experienced by people with an intellectual disability (Chappell 1994). Furthermore, such research has consistently identified that a significant number of people with an intellectual disability experience limited social relationships and few friends. While it would not be accurate to suggest that all people with an intellectual disability are lonely or dissatisfied with their social networks, the comment made by Richardson and Ritchie (1989) sums up the conclusion of much research in this area:

> *Yet it remains the case that in terms of their day-to-day relationships far too many lead impoverished lives.*

On the basis of this understanding the area of friendships in the lives of people with an intellectual disability has received tremendous attention over the past decade. People with an intellectual disability, parents, educators, disability support providers and researchers have all reflected on this critical area and put forward diverse perspectives on how to establish, encourage, facilitate, build, or enhance friendships in the lives of this group of people. This part of the review on adult relationships will outline factors important to consider when addressing the issue of **friendships** in the lives of adults with an intellectual disability.

What is friendship?

Many researchers have commented on the difficulty of defining the term friendship. (Bayley 1997; Chappell 1994; Lutfiyya 1991; Perske 1989). The complex and subtle emotions involved in friendship as well as the diverse range of relationships that are subsumed under the title "friendship" contribute to this difficulty. Chappell (1994) contends that friendship can be used to describe a wide range of relationships which may change over time as people develop new friendships and lose contact with old ones. Bayley (1997) states that friendships are formed and carried on within the context of a variety of relationships. Lutfiyya (1991) provides a comprehensive definition of friendship:

> *Friendships are enmeshed in the social and cultural contexts in which the friends find themselves. All human beings both internalize and are externally influenced by the society in which they live. Each friendship is individually created, maintained, and/or changed over time, within the structure or framework of the larger world that is internalized in each person. Friendship can take on many shades of meaning, and the people who are friends will possess their own*

27

perspectives on their relationship and their experiences of the phenomenon (p 233).

As the focus on friendships in the lives of people with an intellectual disability has increased researchers have attempted specifically to identify the meaning of friendship when it involves people with an intellectual disability.

Richardson and Ritchie (1989) suggest that there are three distinct functions which relationships fulfil for this group of people: intimacy, company, practical help.

> *Friends are people who listen, who understand, who provide the opportunity to share experiences and emotions... The engagement that friendship brings confirms and strengthens people's sense of being valued and valuable...At its deepest level it provides intimacy...A second important function ...is company... Friendships also have a function of providing practical help... Friendship is not only about taking it is equally about giving.*

This last statement refers to the notion of reciprocity. Reciprocity is identified consistently as being fundamental to friendships generally and will be explored in more depth during a discussion of the barriers to friendships for adults with an intellectual disability in this section of the review.

In order to emphasise the importance of friendship for people with an intellectual disability researchers with the Roeher Institute (1990) outlined the critical functions that friendship can provide for people with an intellectual disability. These functions were: intimacy and affection; feeling valued; companionship; taking risks; breaking away from services; support and advocacy; greater chance of a normal life; and acceptance. This group of researchers acknowledged the obvious overlap of some of the functions they identified and saw this as illustrating the critical roles that friendship plays in many different areas of people's lives.

O'Brien and O'Brien (1993) adapted Mary Hunt's (1991) analysis of friendship in order for it to encompass the range of friendships experienced by people with an intellectual disability (including those with severe disabilities). Hunt is of the view that friendship (generally) forms the goal of human community and defining image of ethical relationships. She identified four dimensions as critical components of friendship: love; embodiment; power and spirituality. O'Brien and O'Brien retained the two dimensions embodiment and power but chose to replace love with the label attraction and spirituality with the label community. While making it clear that they do not see these four dimensions as defining friendship exhaustively, O'Brien and O'Brien believe these dimensions are relevant to people with an intellectual disability particularly in relation to the difficulties this group can experience in establishing and maintaining friendships. They summarise the significance of the adapted dimensions in the following way:

> *The community aspect is important because people with developmental disabilities risk social devaluation...The power aspect matters because people with developmental disabilities typically have less power than the amount people without disabilities take for granted... The embodiment aspect is important because people with developmental disabilities risk losing friends simply because they need assistance to undertake activities that lead to or express friendships...*

Finally the aspect of attraction matters because people with developmental disabilities have just as much capacity for friendship as any other people do (p 13).

This analysis of the meaning of friendship in the lives of adults with an intellectual disability gives a very clear indication of some of the barriers to friendships for adults with an intellectual disability. Such barriers will be discussed later in this section.

In order to ascertain the meaning of friendship Lutfiyya (1991) conducted a qualitative study which explored the relationships of four pairs of friends. The friendship pairs all involved one person with an intellectual disability and one person who did not have an intellectual disability. All the non-disabled friends were white and middle class. All of the disabled friends had verbal communication.

Lutfiyya provided an analysis of the meaning of friendship based on the in-depth interview and observation data that she collected for the study. She contended that while the specifics of each friendship were unique, participants shared similar expectations about the characteristics of friendships involving people with an intellectual disability. The first of these characteristics was identified as a feeling of mutuality or of being connected. Practical assistance and emotional support, support to break the rules (eg, by questioning the rules and regulations of a support service) and inspiration were all elements of mutuality or feeling connected. The second important characteristic of friendship was that the friendship must be freely chosen and given (ie, voluntary). This characteristic signals just one of the difficulties in considering how to meet the needs of people with an intellectual disability through the provision of services and/or programs. The third characteristic related to the fact that all the non-disabled friends felt that accepting a certain level of responsibility or obligation for supporting their friend was a necessary part of the friendship.

It is important to point out a significant methodological issue associated with developing an analysis of, or theoretical framework for the meaning of friendship. Given the nature of their primary disability, their reduced life experiences, and the complexity of defining friendships generally, it is often difficult for people with disabilities to articulate what their social relationships, including their friendships mean to them. Because of these difficulties researchers often rely on the interpretations of the non-disabled friend in order to understand the nature of a particular friendship. This reliance has the potential to result in two different but inter-related issues.

Firstly, an over-reliance on information received from a non-disabled friend creates a situation where the meaning of friendship (and consequently the "models" of friendships developed) is based on the experiences of the non-disabled friend and may or may not reflect the experiences of the person with a disability. The second issue related to this point is that friendships existing **between** adults with an intellectual disability may become devalued as there may be no easy way of gaining access to the detailed meaning of the relationship for the people involved.

The role of friendships in the lives of children with an intellectual disability

Before progressing to a more comprehensive discussion of friendships and their role in the lives of adults with an intellectual disability it is important to summarise briefly the experiences of children with an intellectual disability. The value of friendship in the lives of children is no less important than it is in adulthood. The presence of even one close friend in a child's life is extremely important to that child's sense of self, ability to get along with others in adult life, and to achieve happiness and a sense of belonging (Staub 1998). Parents and teachers instantly recognise the significance of friendships in children and young people's lives, and the loneliness of those who do not have friends (Dunn 1993 cited in Smith 1998). Despite this understanding, however, children with an intellectual disability continue to be lonely and to have few friends (MacArthur and Morton 1999).

Isolation itself is disabling (MacArthur and Morton 1999). As well as having a negative impact on quality of life, isolation increases the vulnerability to abuse experiences by children (and adults) with disabilities (Strully and Strully 1992). According to Richardson and Schwartz (1998) the development of peer relationships is one of the most important tasks of early childhood and all children need to experience and participate in a variety of social relationships in order to develop social competence.

Parents and families of children with disabilities have longed for years for their children to have meaningful and lasting friendships with others and have a particular desire for their children's life and relationships to be as typical as other children's (Grenot-Scheyer, Staub, Peck and Schwartz 1998). Parents have, however, commented on the high level of commitment and energy they need to expend in order to support their children to make friends. The time and resources required to support their children's friendships are sometimes untenable in the context of other demands associated with caring for their children with disabilities. This makes it important that the school environment is an area that actively promotes and supports children to develop social relationships and friendships. Smith (1996) pointed out that when teachers use their professional skills to support and nurture the development of relationships and friendships, children with disabilities within inclusive settings are afforded extensive opportunity for learning with and from their peers.

In considering contextual issues in Early Childhood centres and schools in New Zealand MacArthur and Morton (1999) point out that such environments have the power to nurture, or to prevent, the development of positive and supportive social relationships. These authors contend that teachers and schools can implement strategies that nurture friendships. Such strategies include: thinking about the current and long-term benefits of friendships and relationships for all children and young people; creating opportunities for interaction; managing the classroom environment in ways that encourage positive interactions amongst all students; and making sure that individual supports that may be required by students with disabilities do not become barriers to social interaction with their peers (eg, prolonged contact with teacher aides may inhibit a disabled child's ability to interact with his or her peers).

Consideration of these kinds of issues is also outlined in recent American research on friendships between children with and without disabilities in inclusive educational settings (Staub 1998). Staub concluded that a number of factors related to the classroom environment contribute to greater potential for friendships to develop between children

with and without disabilities. Such factors included: time and opportunity; emphasising the positive characteristics of all children providing intentional support (teaching children who do not have disabilities how to interact with, support and respond to children with disabilities); and fostering a sense that everyone "belongs" or is part of the classroom culture.

Children's experiences of friendships, social relationships and social networks, and the consequent development of social competence, are critical to their adult lives. Due to decreasing segregation and increased involvement in their respective communities, today's children have a greater potential than ever before to break the pattern of social isolation for people with an intellectual disability. To fully utilise this potential, however, educators, parents and communities need to continually reflect on how to encourage and support the social relationships of children.

The role of friendships in the lives of adults with an intellectual disability?

What adults with an intellectual disability say about friendships

In order to be able to engage in any meaningful discussion of friendship it is critical to understand how adults with an intellectual disability view the friendships they experience. While sometimes facing difficulties in having their voices and experiences heard, people with an intellectual disability are increasingly articulating their views on this issue. This action can be credited to the notion of self-determination for people with an intellectual disability and an increasing recognition by disability researchers, educators and support services that people with an intellectual disability themselves are the best people to inform research and practice in the area of friendships.

In a recent book focusing on the experiences of women with an intellectual disability Janice Slattery (2000) reflected on the importance of friendship in her own life:

> I have lots of friends from school and work. I like going out with them, just being together and talking. Friends are important. Without friends you've got no one (p 91).

New Zealand woman Avis Hunter (1997) completed and published her life history which detailed her experiences in and out of institutions. Avis credits the presence of friends in her life as being critical to her ongoing happiness and well-being. However, she also highlighted a common experience of many people with an intellectual disability through discussing her own friendship experiences. Hunter wrote:

> I get angry and upset when people don't stay part of my life. Almost everyone comes and goes. That is disappointing to me.

She also emphasised that a focus on the positive aspects of deinstitutionalisation can overlook the loss of important friendships that sometimes occur for people with an intellectual disability.

One day I heard I was going to move from Cherry Farm. I was happy about that. I was worried that I would not get to see my friends any more though. I have lost a lot of friends that I knew when I lived in Cherry Farm because I've lost contact with them since I've been in the community.

Richardson and Ritchie (1989) conducted research that was concerned with understanding the impact of close friendships in the lives of people with an intellectual disability. As part of this study they asked adults with an intellectual disability who did not have a close or "best" friend to talk about what they believed such a friend would add to their lives.

I'd go up to them and say 'would you be my friend to stay with me for good?' I want someone to come up here and say 'right, we'll go out and enjoy ourselves.' A friend I could really rely on and I could give everything I want to (p 26).

The importance of friendship

These comments clearly indicate why people with an intellectual disability perceive friendships as important in their lives. Researchers have also spent a great deal of time identifying and analysing the impact of the presence or absence of friends in the lives of this group of people. Friendship means that people's sense of themselves as people who are valued and valuable in their own right is both confirmed and strengthened.

The impact of not having friends can be devastating. For adults with an intellectual disability poor mental health and wellbeing have been linked with loneliness caused by a lack of friendships or other positive social relationships. Amado (1993) makes the point that it cannot be assumed that a person is not lonely simply because people are always around him or her. This point is particularly pertinent to the lives of people with an intellectual disability who utilise services and are constantly in the company of others but whom often experience a paucity of friendships and/or positive social relationships. Amado identified loneliness as having an effect on physical well-being, mental health, and behaviour. He contends that having friends is *"not a luxury but a necessity to life"* (p 83).

Friendships with disabled friends

An over reliance and focus on friendships involving adults with and without an intellectual disability has led researchers to caution against the dangers of devaluing the friendships that people with an intellectual disability enjoy with other such labelled individuals. Research which focuses on friendships existing between adults with an intellectual disability is scarce. Much of the knowledge able to be accessed about such friendships has been gleaned from anecdotal accounts or life stories conveyed by people with an intellectual disability themselves (Hunter 1997; Slattery et al 2000). It is important to note that the concepts of normalisation and social role valorisation have contributed to a situation where it is viewed as more valuable for people with disabilities to have friendships with non-disabled people. This may reduce adults' opportunities to experience intimate and/or sexual relationships in their lives as such relationships usually

occur between adults who have an intellectual disability. (Intimate and sexual relationships comprise the focus of Section four of this review on adult relationships.)

Friendships with non-disabled friends

As was mentioned earlier, it is more common for research in the area of friendships to focus on the relationships that exist between adults with an intellectual disability and a non-disabled friend. One reason for this emphasis is that it is easier to access information relating to the friendship through the non-disabled friend. The research in this area largely falls into two distinct categories: non-disabled friends' perceptions of their friendships with adults who have an intellectual disability (including inspirational accounts of friendships); and the identification of strategies to promote relationships between adults with and without disabilities.

Green, Schleien, Mactavish and Benepe (1995) conducted a study which explored non-disabled adults' perceptions of relationships in the early stages of arranged partnerships with peers who had an intellectual disability. This study found that through joint participation in community recreation activities the non-disabled participants were cautious, yet optimistic about the possibility of developing friendships with their peers. On closer examination of their perceptions, however, the non-disabled friends perceived and described their developing friendship relationship as being characterised by a big brother/big sister quality. As well as gaining a sense of satisfaction and enjoyment from the relationship the non-disabled participants felt obligation and altruism toward their friend with an intellectual disability. This combination of feelings allowed them to form a positive relationship with their peer without including that person into their broader social network. (It must be noted that the non-disabled participants in this American study were college students who were receiving credits toward partial fulfilment of class requirements for participating in this study).

A study conducted by Lutfiyya (1991) demonstrated very clearly that genuine friendships do exist between people with and without an intellectual disability. This study found that each pair of participants actively created their friendship with one another and played different roles within the friendship. While each friendship pair was unique, Lutfiyya contended that the friendships all shared a number of characteristics. These included: the mutual, exclusive and voluntary nature of the friendship; the rights, obligations and responsibilities of friends to each other; and the positive regard or affection found between friends.

Lutfiyya also made some other important observations relating to friendships between adults with and without a disability. She emphasised that the participants in this study recognised the fact that although their obligations to each other sometimes may have seemed demanding, they were responsibilities that had been freely chosen. Furthermore, although some of the friends talked about experiencing anger, hurt or disappointment within their friendship, they still thought of each other with appreciation. These observations are extremely important because they highlight the similarities between friendships in general and friendships involving adults with and without a disability in particular. Disappointments within friendships do occur and people with an intellectual disability should not be protected from friendships in an attempt to avoid such disappointments.

Traustadottir (2000) provided a critical analysis of the friendship between two young women, one of whom was labelled as being profoundly deaf, intellectually disabled and as having challenging behaviours. The non-disabled woman had "volunteered" to be a friend through a friendship program. Traustadottir's research highlighted the rewards and difficulties evident in friendships between adults with and without a disability. The rewards for the non-disabled friend included: the relationship she developed with the disabled woman's mother (who needed to be actively involved in supporting the relationship; the feeling that she was making a difference to her friend's life by increasing her social experiences and networks; and as being seen as a "special and committed" person for devoting so much time to her disabled friend.

The difficulties that the non-disabled friend experienced in attempting to maintain her relationship with her disabled friend were also apparent. Among these difficulties were the frustrations associated with not being able to communicate effectively with her friend and her inability to understand or to respond appropriately to her friend's challenging behaviours. Traustaddotir interpreted the rewards and difficulties apparent in this friendship, as reflecting the **love** and the **work** often involved in such relationships. She also challenged friendship researchers and/or those involved in reporting on friendship programmes or initiatives to reflect accurately the difficulties, as well as the rewards, of such friendships. Traustadottir said:

> *…much of the disability literature falls short of capturing the complex nature of friendships between people with and without disabilities. Moreover, much of this literature presents an over-romanticized picture of these relationships, and many authors shy away from discussing the difficulties. This trend in disability literature to paint a rosy picture of friendships between people with and without disabilities and the over-emphasize (sic) the positive sides of relationships makes life difficult for [friends] (p 130).*

Friendships with staff

Because paid staff feature heavily in the lives of people with an intellectual disability it is unsurprising that attention has been paid to the social relationships, including friendships that exist between "staff and clients." Most significantly there is debate as to whether people paid to be in the life of a person with a disability can actually be considered to be "friends". Researchers have cautioned against the danger of perceiving all relationships between paid staff and adults with an intellectual disability as friendships (Lutfiyya 1993). However, it is clear that friendships can, and do, exist between adults with an intellectual disability and paid staff but that it is important not to exaggerate the extent to which friendship is a feature of the relationships that occur between these two distinct groups of people.

Lutfiyya (1993) is of the view that it is often difficult to determine whether such a relationship is a friendship as a result of the way accounts of friendships are presented in the literature. Lutfiyya contends that accounts of friendship between staff and clients fall predominantly into three categories: parent narratives; stories of professionals who befriend and advocate on behalf of individuals with an intellectual disability; and inspirational accounts of friendships (which are often intended to illustrate the outcomes

of a successful friendship program or initiative). She also outlined some of the conflicts or difficulties that can affect the development of friendships between paid staff and the individuals that they support. Such conflicts relate to a high rate of staff turnover and to issues created by a "conflict of interest" (ie, that a person is both an employee with a particular status within an agency and a personal friend to someone who is often under the "control" of the same agency).

Evans and Murcott (1990) also addressed this issue in a study which included a focus on the friendships of individuals using a disability service in Wales. This research highlighted the strategic involvement of staff in the area of friendships and relationships in the lives of these adults. Staff either attempted to establish relationships on behalf of those with whom they worked, or they themselves adopted the position of surrogate friends. However, the researchers described these surrogate friendships as being characterised by the staff/friend taking a parental-type role.

The impact that staff can have on the ability for adults with an intellectual disability to meet friends and maintain friendships cannot be underestimated. For this reason it is important to value the many instances in which individual paid staff or disability services provide excellent support to people in an environment where mutual respect, but no friendship exists. Marquis and Jackson (2000) make this point very clearly.

> *Despite policies and practices which encourage the social integration of people with an intellectual disability in mainstream society, unless people have the ongoing support of natural family and friendship networks, expansion of roles and relationships, and social contact may be limited and lacking in relational richness. It is for this reason that relationships between people who use and work in services, may become crucial to the development of personal identity and self worth (p 422).*

Adults' abilities to exercise control over decision making may be affected in many different ways by the presence of staff. Stancliffe (1997) noted that staff presence can have a limiting effect on adults' opportunities to exercise choice freely. Felce (1996) argued that the primary fault in the behaviour of direct care staff is a lack of sufficient social interaction with adults with an intellectual disability who use services. This point is reiterated in McDonald's (1997) New Zealand study on staff responses to individual's communication attempts. People with lower levels of independent behaviour and greater communication challenges usually receive fewer positive and responsive interactions than their more able peers. These findings which focus on the way direct care staff **interact** with adults with an intellectual disability also highlight the reliance that many adult users of disability services have on staff to develop friendships and social relationships.

Myers, Ager, Kerr and Myles (1998) contend that to ensure that people are both physically and socially a part of their community that the role of some staff may need to extend beyond facilitating the social participation of individuals to being a key component within someone's social network. By ensuring that adults are able to maintain contact with existing friends and family, and that they are afforded with opportunities to broaden their social networks, staff can be pivotal in the development and continuity of friendships. This issue is particularly critical for adults who may have communication difficulties. Often staff need to facilitate strongly to achieve opportunities for social interaction for this group of people. Other ways in which staff behaviour can enhance on

or impinge on the social relationships and friendships of adults with an intellectual disability are referred to in the "barriers to friendships" section of this review.

What are the barriers to friendship for adults with an intellectual disability?

Given the importance and function of friends in the lives of adults (and children) with an intellectual disability and that the absence or paucity of friends is a common experience for this group of people, a number of researchers and disability service providers have spent time identifying the barriers to friendships and social relationships for people with an intellectual disability. Researchers with the Roeher Institute (1990) identified barriers to making and maintaining friendships and other social relationships as being a result of:

- inadequate social skills/social competence
- poor self identity/self concept (this is linked to both self confidence and friendship
- lack of financial resources
- lack of transport
- living arrangements
- few opportunities to meet other people
- inaccurate attitudes or assumptions (ie, people with an intellectual disability do not need/want friends)
- lack of experience of close relationships
- perceived inappropriate behaviours
- structural barriers (eg, services that do not see friendships as being important).

Richardson and Ritchie (1989) assert that close friendships cannot be generated simply because they are desired. These researchers contend that there are essentially two general prerequisites that enable friendships to develop – **opportunity to meet other people and the ability to develop and sustain relationships with them.** They go on to identify the two most important factors within friendships as being continuity and reciprocity.

Continuity

The issue of continuity or social network stability has been identified as being an important indicator of lifestyle quality for adults with an intellectual disability. Often such adults are compromised in their ability to achieve a level of continuity in their friendships and social relationships because they are dependent on parents or paid staff to provide continuity. Newton, Olson and Horner (1995) conducted a study which explored the factors that influence the stability of social relationships between adults with an intellectual disability and other community members. The study found that relationship stability was increased if friends had previously worked as paid staff with the individuals with an intellectual disability; if the friends were willing to overcome logistical barriers that might otherwise have impeded the friendship; and if the relationship was perceived to be a reciprocal one. These authors acknowledge that social stability is an insufficient criterion by which to describe a "friendship" but suggest that creating socially stable relationships is a logical necessity for developing a relationship that may become a friendship.

Reciprocity

There is often an assumption that people with an intellectual disability cannot have reciprocal friendships because they do not have anything to "offer" the friendship. In recent research conducted by the Donald Beasley Institute (2001) women with an intellectual disability reflected on the importance of being able to be "good friends". For the women that took part in this study being a "good friend" was linked strongly to their ability to provide information and practical and/or emotional support to friends when they were unwell. This research clearly indicated that the women with an intellectual disability who took part in this study had an understanding of the importance of reciprocity in friendships and that they were motivated to gain skills that could help them achieve this.

Social Skills

A source of disagreement in the professional literature has concerned the value and necessity of social skills training for people with an intellectual disability in order to prepare them for maintaining successful social relationships (Jameson 1998). Amado (1993) challenged the need for programmes aimed at increasing people's social skills and/or decreasing people's challenging behaviour **before** such programmes allowed the adults using them to have contact with other community members. Amado contends that programmes of this kind perpetuate the experience of loneliness and social isolation. An example of enabling adults to develop social skills and appropriate social behaviour whilst being supported to increase their social network size is reported by Barrett (2001). In this project staff received training in recognising and utilising opportunities for social skill development and social interaction for the adults with an intellectual disability with whom they worked. Adults with an intellectual disability received social skills training but they received it within the context of their everyday interactions with other people.

The role of families in the development of friendship

In recent research by Bigby (2000) which explored the lives of older adults with an intellectual disability one participant "Bronwyn" talked about how she felt her mother had overprotected her and denied her opportunities to build social opportunities. When talking about her mother "Bronwyn" said:

> *She wouldn't let me go out. She didn't think I was as old as I am. She treated me like a little girl and she still didn't think I was grown-up. She wouldn't let me be friends with anybody. She wouldn't even let me talk to anybody. There were a lot a people I could have talked to that I liked. I used to go shopping with mum but she wouldn't let me talk to anybody up at the shopping. She didn't used to let me do anything. She was very protective of me (p 75).*

This account provided by an adult with an intellectual disability highlights the fact that some families actively prevent their family member with an intellectual disability from having the opportunity to meet people or to make friends. Bayley (1997) explored the role that families played in the social relationships and friendships that adults were able to experience. He found that families could be categorised on a continuum characterised by

those who actively encouraged and supported social relationship development, and those who actively prevented their disabled family member from meeting new people.

Structural barriers to friendships

People with an intellectual disability frequently are reliant on other people (such as parents or paid staff) for support in many different areas of their lives and unintended social barriers can result (Werner, Horner and Newton 1997). Nisbet and Hagar (1988) contend that such barriers are caused by the fact that paid individuals fulfil socially supportive roles in the lives of people with an intellectual disability that are typically filled by peers. They argue that the presence of paid staff may: remove the need for simple instances of support; engage an individual in a "social bubble" of on-going interactions that others find hard to penetrate; limit the opportunities that a person with a disability has to contribute in social situations; and stigmatise or isolate a person with an intellectual disability.

Bayley (1995, 1997) is of the view that barriers to social inclusion, relationships, and friendships for adults with an intellectual disability should be confronted by working with people and organisations in the community to enable them to respond adequately to this group of people. Bayley identified the following strategies as being critical to the process of encouraging social networks and friendships:

- working with, and gaining an understanding of local organisations
- assisting such organisations to build links with adults with an intellectual disability
- identification of mutual needs
- understanding the overall social and political context of the community
- finding ways in which disability staff and services can support the interactions between adults with an intellectual disability without controlling or disrupting them
- paying attention to the process by which friendships are encouraged to ensure that people with an intellectual disability themselves have maximum control over their lives
- being alert to the range of bodies, groups, organisations and/or services that could be involved.

Issues for adults with severe disabilities or communication difficulties

Despite the ideals that people with severe disabilities would develop new and personal relationships when provided with support to live in their local communities, research suggests that this is rare (Jackson 1997). Werner, Horner and Newton (1997) conducted research with three men with a severe intellectual disability which had the aim of identifying and reducing structural barriers to friendships in the men's lives. Support staff who worked with the men were interviewed in order to determine structural barriers to social life.

Structural barriers to social life were identified as including: lack of staff knowledge of what activities each individual enjoyed being involved in and with whom; lack of practical information (eg, phone numbers, addresses, etc) to enable them to contact potential companions; lack of knowledge of past friends. The men with severe disabilities

who took part in this study were not well known by the staff who worked with them. Because staff did not know a great deal about each of the men's history, experiences, preferences, and modes of communication there was little real opportunity for the men to be supported to develop social relationships or friendships.

Werner, Horner and Newton suggested a range of practical strategies to assist staff to minimise the significant barriers to social life that these men faced. Such strategies included: keeping a personal schedule so that all staff could be informed of planned social activities; developing a personal information sheet so that important personal information relevant to supporting friendships and social relationships did not become "lost"; keeping a friendship form containing practical information about past, present and future friends; and compiling and maintaining a photograph file depicting the social life of each of the men.

Issues for older adults with an intellectual disability

Research has also indicated that barriers to friendships can be particularly challenging for older adults with an intellectual disability. In a study focussing on the day activity and leisure needs of older people Bigby (1992) interviewed older adults directly to gain their views about the activities they were involved in, and their needs and aspirations in this area. Of the seven participants in the study two had no friends at all while the remaining five participants reported having few friends. Bigby asserted that a lack of friendships and social relationships in the lives of older adults could be strongly linked to their limited community skills and experience.

Is there a role for support services in promoting positive friendships?

Support services or programmes designed to promote positive friendships and social relationships for adults with an intellectual disability need to be based on the premise that relationships are central to their lives. It is essential for those living and working with people with an intellectual disability to be alerted to the importance of friendship and how adults with an intellectual disability can be supported in this area of their lives. A number of different approaches have been taken to support or facilitate the process of developing friendships for people with an intellectual disability.

One-to-one or matching

One-to-one or matching programmes are a common approach used to facilitate friendships. They tend to operate on a formalised "volunteer" approach and usually involve matching or connecting a person with a disability with another person who acts as a friend, companion and/or support person. Often such relationships include the function of advocacy. The appropriateness of one-to-one or matching programmes have been questioned for a number of reasons including:

- the danger that two people who have not "chosen" each other may be incompatible but may feel obliged to continue with the "match"
- the contradictions that arise from the notion of a "volunteer friend"

- the possibility that the formality of the relationship may interfere with the natural progression of a friendship
- the likelihood that no other friendships will emerge from the one-to-one matching effort
- the frequency of volunteer burnout as a result of being the only "friend" the other person has.

Despite these criticisms and the fact that current "friendship" initiatives have tended to move away from this approach, programmes that implement a combination of one-to-one or matching strategies and community networking approaches have been successful in generating positive relationships. This formalised method of facilitating friendships is often necessary when attempting to create opportunities for social relationships and (potentially) friendships for adults who have high support needs and/or communication difficulties.

Self advocacy

The self-advocacy movement is particularly significant in helping self-advocates themselves, families, human services and communities to understand the importance of listening to people with an intellectual disability. Self advocate Pat Worth (1988), for example, articulated the importance of community understanding and involvement in the issue of friendship in the lives of people with an intellectual disability.

> *We all have the ability to listen... Sometimes we just don't use it. We just automatically think "I know what is best for this person"... A friend will listen to our rights and choices. A friend will listen to the person who cannot speak for himself because...they may not say it in words but they can say it in expressions. When you don't know people in the community it is frightening because you don't know if you will have a friend there... We have all had to have people in our lives to support us. It is time to stop punishing us. Give us some friends', reach out and be a friend.*

Creating social networks

Another approach to developing social relationships and creating opportunities for friendships to develop involves focusing on a person's social network. A social network refers to a group of people connected to any one person who fulfil a range of functions related to friendship and support in that person's life (Roeher Institute 1990). People may have more than one social network. The "Circles of Friends" (Perske 1989) and MAPs (Amado 1993) programmes are two well known examples of initiatives based on the utilisation of social networks in order to provide opportunities for social support and friendship.

Friendship projects which utilise social networks to encourage friendships usually take one of two approaches; natural' or contrived. The natural approach refers to a process by which already existing social networks in a person's life are identified. For adults with an intellectual disability it is common for them to need support to utilize this natural social

network and planning can occur in order to work out the "best" way for that person to access and utilise their existing social network.

A planned or contrived approach to creating and utilising social networks has been found to be necessary in supporting some adults with an intellectual disability. Because of a serious lack of social relationships in the lives of many such adults social networks are built or created around a person and sometimes include individuals who are not known to the person with a disability. Positive aspects of the use of social networks to build friendships related to the fact that they provide opportunity for people with an intellectual disability to meet greater numbers of other people more frequently. Criticisms of this model of friendship development largely are related to the fact that there is an increased opportunity for the individual at the centre of such planning to become powerless in yet another layer of "planning" imposed on their lives.

Community building

The notion of community building or "bridging" appears to be the most current approach to addressing the friendship and social support needs of adults with an intellectual disability. This approach is based on the premise that in order to make friends, adults with an intellectual disability need frequent opportunities to meet other people. It is also based on the assumption that people with an intellectual disability need and want to be friends with a range of people and that our communities are willing to be friends with people with an intellectual disability. Successful community building or bridging projects rely on the abilities of skilled communicators. Such individuals also need to have a good understanding of the communities in which they are working, including the range of groups and organisations that could provide the environment for social interaction. Problems associated with this approach have also been highlighted. These largely relate to the concern that a focus on connecting people with an intellectual disability to community groups or organisations may fulfil recreational needs but may not enable the person to develop social relationships that have the potential to lead to friendships. (This aspect of adults' lives will be explored in a later review on community participation and leisure.)

What are the characteristics of "best practice" in terms of services that promote friendships for people with an intellectual disability?

People with an intellectual disability have a much more visible presence and participation in the community than in the past, but they continue to experience a significant lack of friendship in their lives. While some service areas related to the field of intellectual disability lend themselves to the notion of "best practice", the intimate and personal nature of friendship, relationship and connections prevents a prescribed approach. Each person is unique and distinctive, therefore processes to facilitate connections must mirror these same characteristics. Richardson and Ritchie (1989) reflect the view shared by many friendship researchers and practitioners through the following comment.

> *Nor is there one single solution to help friendships develop or to keep them going. The very concept of friendship is a complex one.*

Despite this, researchers and practitioners working with people with an intellectual disability to enhance their ability to have friendships agree on a number of important points. These points can be used to inform the development of initiatives, services and or programmes which have the aim of supporting adults with an intellectual disability to meet friends and maintain friendships.

- Support in the area of friendship development should not be seen as an elective add-on for a few "lucky" adults with an intellectual disability. As well as providing emotional and practical support, friends can offer protection against poor quality services, coercion and abuse. This is particularly critical if the person with an intellectual disability does not have involvement with their family.

- Supports should be designed in ways that help facilitate the development of friendships. Support should be offered not only for access to or participation in community settings, but also for the development of relationships within such settings.

- It is important to get past the dilemma of the artificial friend and to accept that while some people with an intellectual disability require ongoing support and assistance to create and maintain friendships the critical aspect of friendship is an acknowledgement of the individual him/herself and how friends would best fit into that person's life. Efforts to provide both support and friendship need to be created around an individual's sense of identity.

- A focus on friendship must take a broad approach – not one friend per person. The more opportunities a person has to meet other people the greater the chance that a friendship may result from such social interactions.

- Older adults with an intellectual disability may need a specialist community access programme to facilitate access to and participation in activities in the local community which are age appropriate and provide opportunities for social interaction. If older people with an intellectual disability are to lead active and fulfilling lives and participate in an increasing range of generic services, most will need specialist assistance to gain access to such services.

- As essential as friendships are they should not be seen as an acceptable replacement for necessary support services. Many individuals with an intellectual disability are still living in fragile and vulnerable situations with few friends and limited social networks and until this situation is reversed formal support services need to be available to meet the diverse support needs of this group.

- Community development is a critical aspect of increasing the opportunities that adults with an intellectual disability have to be included in the community, to broaden their social networks, and to develop social relationships. Community development needs to be undertaken by individuals who are knowledgeable about their communities and who are skilled communicators.

References

Amado R. 1993. Loneliness: Effects and Implications. In A Novak Amado (ed). *Friendships and community connections between people with and without developmental disabilities.* Baltimore: Paul Brooks Publishing Company.

Barrett J. 2001. Opening the doors to friendship. *Community Living* 14(3): 8-9.

Bayley M. 1997. *What price friendship: Encouraging the relationships of people with learning difficulties.* Somerset: Hexagon Publishing.

Bayley M. 1995. Confronting the barriers to integration. *Community Living* 9(1): 16-7.

Bigby C. 2000. Life without parents: Experiences of older women with an intellectual disability. In K Johnson, R Traustadottir (eds). *Women with an intellectual disability: Finding a place in the world.* London: Jessica Kingsley Publishers.

Chappell A. 1994. A question of friendship: Community care and the relationships of people with learning difficulties. *Disability and Society 9*(4): 419-34.

Evans G, Murcott A. 1990. Community care: Relationships and control. *Disability, Handicap and Society* 5(2): 123-35.

Felce D. 1996. Quality of support for ordinary living. In J Mansell, K Ericson (eds). *Deinstitutionalisation and community living: Intellectual disability services in Britain, Scandinavia, and the U.S.A.* London: Chapman Hall, 117-34.

Green F, Schleien S, Mactavish J, Benepe S. 1995. Non disabled adults' perceptions of relationships in the early stages of arranged partnerships with peers with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities* 30(2): 91-108.

Grenot-Scheyer M, Staub D, Peck C, Schwartz I. 1998. Reciprocity and friendships: Listening to the voices of children and youth with and without disabilities. In L Meyer, H-S Park, M Grenot-Scheyer, I Schwartz, B Harry (eds). *Making Friends: The influences of culture and development.* Baltimore: Paul Brookes Publishing Company.

Hunt M. 1991. *Fierce tenderness: A feminist theology of friendship.* New York: Crossroad.

Hunter A. 1997. *My Life.* Dunedin: Donald Beasley Institute Inc.

Jackson R. 1997. *Community integration: much more than 'being there'*, paper presented at the 33rd Annual Conference of the Australian Society for the Study of Intellectual Disability, Brisbane.

Jameson C. 1998. Promoting long-term relationships between individuals with mental retardation and people in their community: An agency self-evaluation. *Mental Retardation* 36(2): 116-27.

Lutfiyya Z. 1991. 'A feeling of being connected': Friendships between people with and without learning difficulties. *Disability, Handicap & Society, 6* (3), 233-254.

Lutfiyya A. 1993. When staff and clients become friends. In A Novak Amado (ed). *Friendships and community connections between people with and without developmental disabilities.* Baltimore: Paul Brooks Publishing Company.

MacArthur J, Morton M. 1999. 'I'm still trying to make friends…' *Childrenz Issues 3*(1): 38-42.

Marquis R, Jackson R. 2000. Quality of life and quality of service relationships: experiences of people with disabilities. *Disability & Society, 15* (3), 411-425.

McDonald T. 1997. Communication and people with severe intellectual disabilities. Unpublished PhD thesis, University of Otago.

Myers F, Ager A, Kerr P, Myles M. 1998. Outside looking in? Studies of community integration of people with learning disabilities. *Disability and Society* 13(3): 389-413.

Newton S, Olson D, Horner R. 1995. Factors contributing to the stability of social relationships between individuals with mental retardation and other community members. *Mental Retardation* 33(6): 383-93.

Nisbet J, Hagner D. 1988. Natural supports in the workplace: A reexamination of supported employment. *Journal of the Association for Persons with Severe handicaps* 13 (4): 260-7.

O'Brien J, O'Brien C. 1993. Unlikely Alliances: Friendships and people with developmental disabilities. In A Novak Amado (ed). *Friendships and community connections between people with and without developmental disabilities.* Baltimore: Paul Brooks Publishing Company.

Perske R. 1989. *Circles of friends: People with disabilities and their friends enrich the lives of one another.* Nashville: Abingdon Press.

Richardson A, Ritchie J. 1989. *Developing friendships: Enabling people with learning difficulties to make and maintain friends*. London: Social Policy Institute.

Slattery J with Johnson K. 2000. Family, marriage, friends and work: This is my life. In R Traustadottir, K Johnson (eds). *Women with an intellectual disability: Finding a place in the world.* London: Jessica Kingsley Publishers Ltd.

Smith A. 1996. *Quality in early childhood intervention: Does it make a difference?* Paper presented to the New Zealand Early Intervention Conference, Invercargill, New Zealand, September 15-17.

Smith A. 1998. *Understanding children's development,* 4th edition. Wellington: Bridget Williams Books.

Stancliffe R. 1997. Community living-unit size, staff presence and residents choice making. *Mental Retardation* 35(1): 1-9.

Staub D. 1998. *Delicate Threads: Friendships between children with and without special needs in inclusive settings.* Bethesda, MD: Woodbine House.

Strully J, Strully C. 1992. The struggle towards inclusion and friendship. In J Nisbet (ed). *Natural supports in school, at work, and in the community for people with severe disabilities.* Ohio: Paul Brookes Publishing Company.

Taking more control of my health: A health guide for women. 2001. Dunedin: Donald Beasley Institute Inc.

The G Allan Roeher Institute. 1990. *Making friends: Developing relationships between people with a disability and other members of the community.* Ontario, Canada.

Traustadottir R. 2000. Friendship: Love or work? In R Traustadottir, K Johnson (eds). *Women with an intellectual disability: Finding a place in the world.* London: Jessica Kingsley Publishers Ltd.

Werner K, Horner R, Newton S. 1997. Reducing structural barriers to improve the social life of three adults with severe disabilities. *Journal of the Association for Persons with Severe Handicaps* 22(3) 138-50.

Intimate and sexual relationships

The right to an intimate and/or sexual relationship is seen as a basic right for most people. Adults with an intellectual disability have not always been able to have intimate or sexual relationships. Sex and sexuality has often been ignored by parents, caregivers and professionals. Some people feel uncomfortable about the sexuality of adults with an intellectual disability.

In the past people with an intellectual disability have been treated in two different ways. Some people see adults with an intellectual disability as people who need protecting from other members of the community. Other people are scared of adults with an intellectual disability and see other members of the community as needing to be protected. This has meant that it has only been recently that researchers have begun to look at sex and sexuality for adults with an intellectual disability. Sexuality means how we feel about ourselves, how we express our sexuality, and what being a man or being a woman means. Sexuality does not just mean sex!

In the past adults with an intellectual disability have not had many opportunities to talk about their sexuality. For this reason it is hard to find much information about what adults think about this topic. From the information we were able to find it seems that adults want the same kinds of relationships as other people and they want to be respected and valued within those relationships.

Research has shown that women with an intellectual disability do not always feel good about their sexual relationships. Often this is because they do not enjoy the kinds of sex they are having, or they are being sexually abused. Women with an intellectual disability are at a high risk for abuse.

Men with an intellectual disability have had even less chance to talk about their sexuality than women. A lot of the research about men talks about men with an intellectual disability who sexually abuse other people, and issues to do with helping these men to change their behaviour. Other research has been to do with homosexuality or HIV. Researchers are now saying that it is important that we get to hear more about men's experiences of sexuality. Adults who want to have relationships with other adults of the same sex have also found it hard to have people accept their wishes.

Families of adults with an intellectual disability often find it hard to see their sons and daughters as adults. This makes it very difficult for them to accept that adults should be able to lead sexual lives. Staff in intellectual disability services sometimes also believe that adults should not lead sexual lives. Other staff believe that it is their job to help people have intimate or sexual relationships if that is what they want.

Some things that make it hard for adults to experience intimate or sexual relationships are: services who do not want to support adults in the area of sexuality; families who prevent adults from having relationships with other people; adults' own experiences of sexual abuse; and their lack of knowledge about sex and sexuality. Sex education is not

always made available to adults with an intellectual disability. This makes it even harder for them to start intimate or sexual relationships.

This review has shown that:

- adults with an intellectual disability must be seen as sexual beings by families, service providers and the community
- sexuality does not just mean sex. Adults should be supported to experience a wide range of relationships
- adults need safe places where they can talk about sexuality
- adults need access to sexuality education.

ADULTS WITH AN INTELLECTUAL DISABILITY AND INTIMATE AND SEXUAL RELATIONSHIPS

Introduction

The right to an intimate and/or sexual relationship is perceived as a basic right for most people. In the case of adults with an intellectual disability, however, this is a right that is not always able to be achieved. Traditionally, sexuality has been a topic largely ignored by parents, caregivers, and professionals. Many people feel ambivalent or uncomfortable about the sexuality of adults with an intellectual disability. However, as the importance of family relationships and friendships has been realised, increasing attention is being paid to the area of intimate and sexual relationships for adults with an intellectual disability.

This section of the review of adult relationships will discuss the role of intimate and sexual relationships in the lives of adults who have an intellectual disability. It will also identify some of the difficulties and barriers that adults face when trying to create opportunities for intimate and sexual relationships to develop, and suggest strategies which may be useful in increasing adults' personal autonomy in this area.

What is sexuality?

The integration of people with an intellectual disability into society, and the models of care set up around them have always included a sexual dimension (Brown 1994). People with an intellectual disability have frequently been the subject of either fear or myth – they have been seen as asexual or oversexed, innocents or perverts. Historically services have been based on the premise that there is a need to maintain sexual boundaries between people with an intellectual disability and the general public. 'Innocence' models of sexuality suggested the need to protect people with an intellectual disability from predatory members of the public while 'degenerate' models stressed the need to protect the public from people with an intellectual disability (Brown 1994).

Baylis (1992) defined sexuality in the following way:

> *Sexuality is an integral part of what constitutes being a human being. It has many faces, but encompasses maleness and femaleness; self concept; self esteem; sensuality; the state of being sexual; as well as sexual expression, which may or may not include sexual intercourse. As such it cannot be separated from the total personality. Personality in turn is influenced by biological, sociological, spiritual and cultural variables (p 15).*

Melberg Schwier (1994) provided the following interpretation of sexuality and how adults with an intellectual disability experience it.

> *There are many illustrations of our denial that people with disabilities, particularly those with an intellectual disability, are sexual beings. We forget that sexuality is so much more than merely sex; we overlook the need for companionship, conversation, trust, love, an appreciation for who we are as a male or female (p 6).*

Intimate and sexual relationships and adults with an intellectual disability

In conducting this review it quickly became clear that while there is a great deal of information relating to sexual abuse, the need for sex education, and the role of staff and services with regard to issues of sexuality, there is little research that explores and reports the views of adults with an intellectual disability themselves. Furthermore, it is more difficult to find personal accounts written by adults with an intellectual disability themselves which reflect on issues of sexuality. Literature that is relevant to this topic is discussed below.

Heyman and Huckle (1996) found that adults with an intellectual disability who participated in qualitative interviews relating to sexuality had negative or ambivalent feelings about sexuality. Many believed sex was rude, or only permissible in marriage. Such beliefs were instilled by family carers and were strongly reinforced through their experiences within disability services.. Heyman and Huckle also found that the adults who took part in their research had been deprived of sex education or had been misinformed about matters relating to sex and sexuality.

The sexuality of people with mild intellectual disability was assessed by Szollos and McCabe (1995) using the Measure to Assess Sexual and Relational Knowledge, Experience, Feelings and Need (Sex Ken-ID), (McCabe and Schreck 1992). Data were gathered through the administering of the Sex Ken-ID during one-to-one interviews with participants. Data were collected from three groups (adults with an intellectual disability, their caregivers, and a group of people without an intellectual disability) and comparisons were made.

This study found that care staff consistently overestimated the responses of their clients whom they perceived to be more knowledgeable and experienced, have more positive feelings about sexuality and a greater need to know than was indicated by the adults with an intellectual disability. The group of adults who did not have an intellectual disability demonstrated a higher level of knowledge of sex and sexuality, and reported more sexual experience. The exceptions to this were that the group of adults with an intellectual disability had experienced higher levels of abuse and reported equal frequencies of same sex experience.

Issues for women

Women have reflected recently on the issue of intimate and personal relationships in their lives. Slattery (2000) described the process that she went through to get to know her husband. Slattery's account illustrates very clearly that as a woman with a disability she has the same expectations of a 'quality' relationship as most other women. She wants a partner who loves her for herself and offers her respect.

> *I met John at a Southern Regional Council meeting (a disability advocacy organisation) in 1985... And then he rang me and when we saw each other again he asked me out... So we started going out as friends to see if things got serious. And things got serious in the end and that... I'd been out with other guys before John but mum thought they weren't good for me. Then John came along and mum thought John was right for me. And I said to myself, 'Oh, I've found Mr Right at*

long last.' The other guys only wanted one thing only. John liked me for what I am. The other guys wanted me for my body and that is it really. I wanted a guy to love me for what I am (p 96).

It has only been recently that women (in general) have been 'granted' permission to be sexual beings. Such permission is yet to come for women with an intellectual disability (Baylis 1993). Baylis argues that this permission can be facilitated by enabling women to have an increased knowledge about their own sexuality. Increased knowledge, in Baylis', view leads to an enhanced self concept.

McCarthy (1999) made a comprehensive contribution to research in the area of sexuality and women with an intellectual disability. In this study McCarthy investigated how women with mild and moderate intellectual disabilities experienced their sexual lives. The research was based on qualitative interviews with women themselves. In the interviews the women were asked to talk about what kinds of sexual activity they took part in, what sex and sexuality meant to them, the circumstances in which it occurs, and the pleasures associated with sexual activity.

One of the most significant findings of McCarthy's research was that the women with an intellectual disability who participated in the study had a generally negative view of their sexual lives. McCarthy identified four factors which result in this overall negative experience. The four factors are:

- a lack of sexual agency amongst the women themselves
- the actual sexual activity that takes place
- the fact that this is experienced on a predominantly physical level
- the very high levels of sexual abuse which the women experience.

Issues for men

Researchers have begun recently to comprehensively explore the issue of sexuality and how it relates to men with an intellectual disability. In a theoretical paper Cambridge and Mellan (2000) identify a range of key issues for sexuality work with men with an intellectual disability and argue that these issues require greater recognition and attention. Cambridge and Mellan contend that the recognition that people with an intellectual disability have a right to sexual lives has led, inevitably, to a focus on sexual abuse (with a particular focus on the abuse of women with an intellectual disability). The focus on abuse has recently extended to research on the role of men with an intellectual disability as abusers (Brown and Thompson 1997) and the challenges that men with 'difficult' sexual behaviour pose for women support staff (Thompson, Clare and Brown 1997). Other research relating to men has largely been conducted in relation to HIV and homosexuality (Cambridge 1996, 1997, 1999). Cambridge and Mellan suggest that this creates a risk of a pathological approach to men's sexuality and argue that men's sexuality needs more general consideration.

Cambridge and Mellan provide a list of points or topic areas that they believe are critical to group and/or individual sexuality education work with men who have an intellectual disability. The points are summarised as follows:

- understanding the nature of sexuality within and outside relationships and relationships without sex
- the sexual rights and responsibilities of individuals and understanding the responsibilities of men in relationships
- the nature of informed consent to sex, the language and skills needed to negotiate sex and receptive and expressive communication for declining sex
- reciprocity, exchange and affection, and the feelings of sexual partners regarding different sexual acts
- the health, social and legal consequences of different sexual activities
- the importance of privacy, confidentiality and appropriateness of place in relation to sex
- cultural perspectives on sex with men with an intellectual disability
- social perspectives on sex between men and women with an intellectual disability and implications of pregnancy and parenting
- assertiveness skills, personal safety skills
- integrated work on homosexuality, HIV risk, and safer sex
- linking sexual behaviour with sexual identity, and the development of a positive self image
- support and space to more appropriately express their feelings about sex.

In conducting this review of relationships experienced by adults with an intellectual disability it has been clear that there is little current literature available which explores the **personal** views and perspectives of men with an intellectual disability. In response to the disempowerment and lack of personal autonomy of women with an intellectual disability, a great deal of attention has been paid to supporting such women to have a voice in the disability literature. It appears that men with an intellectual disability have not had the same opportunities to reflect on their own experiences of relationship. Furthermore, most researchers and practitioners working in the area of intellectual disability, and particularly in the area of relationships are women themselves and are therefore likely to have a focus on women's issues. Additionally, there are ethical considerations to be addressed for women researchers who wish to work with men on topics of a sensitive nature.

The role of family in intimate and sexual relationships

The issue of sexuality often is a contentious one for families. Parents tend to view their sons and daughters within the 'innocence' paradigm (Brown 1994). Pendler (1993) provides a parent's perspective on the issue of sexuality and people with an intellectual disability. Pendler's comments are centred on the experiences of adults who live in group homes, but the general issues have relevance to those living independently, in a supported flatting situation, or at home with their parents. Pendler put forward her views on how adults with an intellectual disability are perceived.

> *Some professionals and agencies indulge in the tempting proposition of reducing the needs of persons with developmental disabilities to only biological urges and of reducing sex to a simple behaviour that can be programmed away. However the truth is that we do not view our personal loving relationships only from a genital perspective. We have caring and loving relationships, including the desires to touch, caress, and hold hands, and we have to recognize that people*

with developmental disabilities also have the capacity to love and care for others. This recognition should, perhaps, be the first step for parents, professionals and society at large…Encouraging friendships has long been a goal for parents and staff within the human services, therefore, it is necessary to recognize that one of the aspects of friendship must be the subject of sexuality (p 227-8).

Pendler goes on to say that parents must recognise that talking about sexuality does not result in their son and daughter developing sexual feelings – those feelings are already there. Her view is that exposing young people to sexuality education ensures greater protection against risks to their sexual health, and from exploitation or abuse. Pendler concludes by saying that professionals need to remind parents that they have a responsibility to their son or daughter to help them develop an appropriate sexual identity and to provide or allow them to access information that is critical to their ability to make informed choices.

In a qualitative study designed to explore the notions of perceived risks and hazards in the lives of adults with an intellectual disability Heyman and Huckle (1996) focused on adult sexual relationships as a perceived hazard. Data for the study was collected from family carers and from adults with an intellectual disability themselves. Study findings suggested that adults with an intellectual disability were actively discouraged from pursuing sexual relationships. Their family carers felt and expressed a range of views including that, the adult; was not interested in sexual relationships; was not able to understand them; was not capable of acting responsibly, or was at risk of exploitation from, or was a risk to other people. Additionally, some family carers would not contemplate their adult family member being involved in a sexual relationship if they were not in a stable structure such as marriage. However, these family carers also felt that their family member was incapable of fulfilling such a role therefore the opportunity to have a sexual life was denied.

The role of staff in intimate and sexual relationships

The current role of support staff who work in disability services is diverse. Staff are expected to play an active role in many different facets of the lives of adults who have an intellectual disability. It has been common, however for staff to be reticent about supporting adults to assume ordinary sexual roles. Brown (1994) contends that this reticence is a result of an underlying assumption that these roles are off limits to adults who have an intellectual disability. She believes that what is valued for others is greeted with fear and disapproval by members of the public if it is people with an intellectual disability who want to engage in sexual lives.

Brown (1994) poses the question "what would it take to actively support people with learning disabilities" (p 139). The answer to this question, in Brown's view, would see staff: taking a proactive approach in the face of loneliness and social isolation and support adults to meet people and maintain friendships and relationships; providing sexuality education which is accompanied by adults being supported to gain age appropriate experiences (having such opportunities should not, Brown argues, be seen as a "prize for graduation" from sexuality education programmes); engaging with parents to determine how an adult's sexuality could be supported in a manner that meets the family's cultural values; being more vigilant about preventing and/or responding to cases of sexual abuse.

Barriers to intimate and sexual relationships for adults with an intellectual disability

Many factors affect the ability of adults who have an intellectual disability to experience typical sexual development and sexual lives. Brown (1994) provides an interpretation of how the normalisation principle applies to the sexual options of people with an intellectual disability. Using a discourse analysis approach, Brown discusses the role of services in relation to sexuality and adults with an intellectual disability. Brown argues that despite the recognition of their 'abstract rights' (and the inclusion of such principles in policy) there has been a failure to:

> *...break through the barriers of prejudice and isolation and to create real opportunities for people with learning disabilities to live in different kinds of partnerships and family groups or to enjoy a wide range of sexual relationships, contacts and activities (p 123).*

Brown's discussion paper poses the following question.

> *Is there an unwillingness or an inability on the part of services to create opportunities for sexual relationships or support people in sexual partnerships? (p 124)*

The answer to this question, Brown concludes, is that services have an implicit role in the regulation of sexuality and the creation of sexual boundaries.

Jurkowski and Amado (1993) identified a number of factors which have had a strong influence over the ability of such adults to develop intimate or sexual relationships with other people. One of the critical factors was identified by these authors as **segregation**. Many people with an intellectual disability grow up in environments that do not provide culturally valued expectations or positive role models. Segregation is a factor of many people's lives, even when people with an intellectual disability have grown up 'in' the community and in their own families. Despite a philosophical context which promotes inclusion the reality for many such people is that their lives are characterised by isolation, 24-hour supervision and a significant lack of privacy. If people with an intellectual disability are, or have previously been institutionalised the impact of segregation is even more severe.

Jurkowski and Amado cited **restrictiveness** as the second factor which has the potential to impact on the ability of adults who have an intellectual disability to experience an intimate or sexual life. Adults are often the subject of close supervision with resulting restrictions being placed both on their behaviour and the amount of information they are "allowed" to receive. The end result of such practices in Jurkowski and Amado's view, is that adults may end up isolated, overprotected from information and experiences, thus rendering them unprepared to initiate or maintain an intimate or sexual relationship.

Further to this point, Jurkowski and Amado highlight the issue of **privacy** as the third factor impacting on adults in the area of their sexuality and sexual lives. Adults with an intellectual disability and physical impairments often experience an excessive level of touching as necessary health care tasks are performed. These tasks may be carried out by family members, personal care staff, or other human services or educational staff. Cole

(1988) suggested that in the face of this high level of intimate and personal touch some children and/or adults may not acknowledge or be aware of the separateness and ownership of their own bodies. Cole contends that this situation requires medical, professional and other caregivers to negotiate necessary touching of an individual's body to avoid creating an on-going loss of personal autonomy. Cole (quoted in Jurkowski and Amado 1993) made the following statement:

> *It is ironic that persons with disabilities have experienced explicit handling of their bodies for physical care or medical reasons, but at the same time, have often experienced a total void in sexual expression or experience. In addition, many have never spoken or been spoken to directly about sexuality (p 142).*

Jurkowski and Amado highlighted limited levels of **sexual knowledge** and few **socio-sexual skills** as also impacting on adults with an intellectual disability. Given the segregation, restrictiveness and lack of privacy in their lives the fact that they have been unable to acquire sexual knowledge or develop socio-sexual skills is unsurprising.

Same sex relationships

If adults are considered as sexual beings at all, they are always considered to be heterosexual. Little consideration has been paid to adults who wish to pursue same-sex relationships. Given the difficulty that adults with an intellectual disability have in negotiating access to heterosexual relationships, the issues for men and women who wish to be involved in same sex relationships are even more difficult. Appleby (1994) conducted a qualitative study which explored the meanings that women attached to their experiences of being disabled and lesbian. Women with a range of disabilities took part in the study, including one women with an intellectual disability. "Michelle" expressed frustration at the effect that she said paid care providers had on her life. She said:

> *It's not fair for other people to press on you their views (p 25).*

Michelle felt that she had no access to education and no support in the area of sexuality (heterosexuality or lesbianism) at all. She believed this situation could be attributed to the fact that people with an intellectual disability are treated as though they are "stupid". Michelle did not see that gaining access to information relating to sexuality would improve her situation as she argued that she would never have the privacy in which to conduct an intimate, sexual relationship anyway. She was particularly fearful of staff discovering her true sexual identity and identified a need for staff to receive information and training aimed at decreasing prejudice and homophobia. Finally, Michelle's views with regard to her sexuality were shaped by her belief that as a women with an intellectual disability it was hard for her to identify with, or experience any sexuality at all.

Men and women with an intellectual disability who want alternative sexualities (ie, non heterosexual) are likely to be disadvantaged in the area of building identity or gaining membership of groups and networks to affirm their choices (Brown 1994). Men with an intellectual disability who have sex with other men often have not received any education about safer sexual practice. This is sometimes attributed to the fact that although their sexual behaviour is known about, such men are not credited with a gay identity. Their

sexual behaviour is instead kept hidden therefore posing a greater risk to their sexual health.

Sexual abuse

The impact of abuse in the lives of adults who have an intellectual disability cannot be over-estimated. Abuse and exploitation feature significantly in the lives of adults who have an intellectual disability. Sobsey (1994) provides a useful summary of the patterns of sexual abuse that have been identified in the research literature. Sobsey states that both children and adults are at greater risk for sexual abuse. The abuse that these individuals experience is often severe. While children and adults with an intellectual disability may be abused by the same perpetrators as other victims of sexual abuse (eg, family members, neighbours, babysitters), they appear to experience additional risk of abuse from other people with an intellectual disability, and from caregivers whom they come in contact with through disability services. Sobsey emphasises the point that although disability is associated with the risk for abuse, it is important to avoid the assumption that disability is a direct cause of vulnerability. The increased vulnerability, Sobsey suggests, may be associated more with society's response to disability than to disability itself.

Recent research has explored the issue of sexual abuse in the lives of adults with an intellectual disability. McCarthy (1999) found that 14 out of a total number of 17 women who participated in a qualitative study had, within their own understanding of the term, been sexually abused. Of the three remaining women one of the women became extremely uncomfortable when the subject was raised (she did acknowledge that she had been physically abused by a previous partner and her current partner was a convicted sex offender). A second women did not disclose abuse, but support staff who knew her well believed that she had been sexually abused in the past. These findings illustrate graphically the high incidence of abuse in the lives of women with an intellectual disability.

While women with an intellectual disability experience a disproportionate level of abuse (which is often perpetrated by non-disabled men) recent research has focused on the abuse perpetrated by men with an intellectual disability (Brown and Stein 1997). This British research compared cases of sexual abuse of adults with an intellectual disability committed by men with an intellectual disability with cases of abuse committed by non-disabled men. The authors chose to conduct this research because they wanted to explore their impression that abuse perpetrated by adults with an intellectual disability is often explained away as unintentional, the result of a misunderstanding, and/or less likely to cause distress (to the disabled victim).

Data for this study was collected in two separate surveys covering the years 1989-1990 and 1991-1992. Survey respondents were senior staff in intellectual disability services. Definitions were included with the survey questionnaires which made clear that sexual abuse was to be defined and documented from the point of view of the person who had been victimised rather than mediated by the supposed intent or 'competence' of the perpetrator. (The significant ethical issues related to the conducting of this study are reported on in another paper – Brown and Thompson 1997.)

Brown and Stein found that while women predominated as the victims of abuse of both groups, there were slightly more male victims in the sample offended against by men with an intellectual disability. They also found that when men with an intellectual disability were the offenders, services were more likely to handle the matter in house. That is, many services did not seek professional advice, or seek to apply sanctions to the offender through the criminal justice or mental health legislation.

Brown and Stein interpreted these findings as being consistent with the notion that abuse perpetrated by adults with an intellectual disability is minimised if the victim also has a disability. In explaining why services need to take urgent steps to address this situation Brown and Stein made the following statement:

> *The cost of failure and minimization is that other people with an intellectual disability are offered unequal protection in the law and in their daily lives, while the men themselves run the continued risk of incarceration if they repeat their abusive behaviour outside the closed world of service agencies. No one wins while the abuse of one service user over another is glossed over again, and again, people lose (p 224).*

Further to this point McCarthy and Thompson (1996) suggest that some features of service design in themselves make sexual abuse more likely to occur. McCarthy and Thompson approach this issue from the perspective that the biggest single group of perpetrators of sexual abuse against people with an intellectual disability are in fact other service users. These authors discuss a range of strategies that could be implemented in services to decrease the risk of abuse for service users. Enabling adults with an intellectual disability to choose to live in single sex settings is one such strategy. The argument that this option will not protect vulnerable men from abuse should not, in the authors' view, preclude it from being a strategy available to vulnerable women.

Another area that could be considered for re-design is the size of services. The more people that use and work in a service obviously increase the chance that a person with an intellectual disability may be abused. McCarthy and Thompson also contend that when services are very small and isolated, and service users do not get the opportunity to mix with other people that people are vulnerable to sexual abuse. McCarthy and Thompson also advocate for the need for greater understanding of abuse as an abuse of power and for senior staff to have such an understanding. Finally, McCarthy and Thompson contend that if there is to be a serious effort at eradicating sexual abuse from services there needs to be an examination of attitudes towards all other kinds of abuse that take place.

Furey and Keharhahn's (2000) research also focuses on the issue of abuse and how it is perceived by services. A survey of supervisors, mangers and executives in intellectual disability services was administered. The results of the survey indicated that such staff were lacking in knowledge about the characteristics of potential victims of abuse, characteristics of abusers, and overall facts about abuse. Furthermore, survey respondents themselves identified a need for training in this critical area.

The research reported here illustrates the extent to which sexual abuse is a feature in the lives of men and women with an intellectual disability. It also emphasises the fact that while women are the most common victims of abuse, men with an intellectual disability are also abused. In order to achieve positive results in reducing the incidence of abuse,

attention needs to be paid to several areas. Men and women with an intellectual disability need information about abuse and opportunities to develop assertiveness skills which could reduce their vulnerability to abuse. Men (and women) with an intellectual disability who are the perpetrators of abuse also need to receive appropriate education and programmes aimed at eliminating abusive behaviour. Finally, services need to display zero tolerance of all forms of abuse and consider ways to limit the opportunities for abuse to occur within services.

Sobsey (1994) explored the factors that contributed to the likelihood that a person with an intellectual disability could experience abuse. Sobsey identified that 77 percent of abuse cases were for: reasons of impaired judgement or knowledge; lack of assertiveness; inability to communicate mistreatment; or too much trust in others. These findings provide a clear indication of the need for adults with an intellectual disability to receive opportunities for sexuality education.

Sexuality education

Sexuality education is not always made available to adults who have an intellectual disability. While other students receive such education as part of the school curriculum, students with an intellectual disability have frequently been excluded from these lessons. Furthermore, with regard to adult services, it is common for men and women with an intellectual disability to receive "reactive" rather than "proactive" sexuality education. That is, people receive access to information, education and/or sexuality counselling if they have displayed "problem" sexual behaviour.

Research has shown that sexuality education for adults with an intellectual disability needs to take into account the previous limitations that such adults may have had in relation to their ability to gain even a basic level of understanding in this area. In a recent study focusing on health education and women with an intellectual disability in the New Zealand context it was found that a significant number of the participants had been denied access to any sexuality education in the past (Mirfin-Veitch, Bray, Walker and Moore, in preparation). This lack of knowledge had tremendous impact on the women's ability to take control over their own health needs, including needs relating to their sexual health (for example, many of the women were unfamiliar with the need for cervical screening). This means that adults with an intellectual disability are tremendously reliant on parents or paid staff to ensure that their basic health needs are met. In the area of health, and particularly the area of sexual health, adults with an intellectual disability are disadvantaged in their ability to achieve personal autonomy.

Bambury, Wilton and Boyd (1999) responded to what they perceived as a particularly urgent need in the New Zealand context by developing, and evaluating two socio-sexual education programs for New Zealand adolescents/young adults with a mild intellectual disability. The first program was developed using a slide based approach, the second program utilised video to deliver sexuality education. Eighteen adults, all of whom were in the age range of 17-46 years participated in the study. Fifteen of the participants were male. Each of the participants lived in the community and all attended a community studies course at polytechnic.

To achieve the aims of the study two teaching programs were developed to increase socio-sexual knowledge and to positively influence sex attitudes of adolescents/young adults. Each of the programs focussed on eight specific areas: self esteem; friendships and relationships; puberty; body parts and functions; sexual feelings and being sexual; assertive, protective and appropriate behaviour; sexually transmitted diseases (including AIDS); and contraception/pregnancy. Each program was conducted over a period of eight weeks (one session per topic/per week). Slides or video footage was used to emphasise key teaching points and attempts were made to draw upon the knowledge and previous experience of the students. In order to fulfil the evaluation component of this study students completed the Socio-Sexual Knowledge and Attitude Test (SSKAT), (Wish, McCombs and Edmonson 1980) prior to participating in the education sessions and them directly following the completion of the eight-week course.

The study found that the eight-week course did result in knowledge gains in the area of socio-sexual knowledge by participants in both the slide-based, and the video-based programs. It also suggested that participants had more positive attitudes about sexual matters following participation in one of the programs. There was no significant difference in the knowledge or attitude gains between those who had participated in the slide-based program and those who had participated in the video based program. Authors of this study stated:

> *While the present results indicate that program development in this area is worthwhile, it is important to note that a focus on knowledge-gains per se in such programs is insufficient (p 211).*

Researchers involved in a recent New Zealand study support this (Mirfin-Veitch, Bray, Walker and Moore, in preparation). In this study which included the development, and delivery, of a health education programme for women who had an intellectual disability (of which sexuality education comprised one component), knowledge gain was just one outcome of the study. The study incorporated qualitative evaluation procedures both during (Mirfin-Veitch, Bray, Walker and Moore, in preparation), immediately following and three months following the completion of the health education programme (Becker 2001). During such evaluations the women were asked to identify what they perceived as the most important aspects of participating in the programme. Almost without exception the women participants valued the opportunity to meet other women, and develop social relationships and friendships as being the most valuable part of the group experience. This finding emphasises the importance of viewing health and/or sexuality education as providing a greater range of opportunities for adults with an intellectual disability than only knowledge gain.

Sexuality education provided for adults with an intellectual disability needs to be clear, concise, and pitched at the individual's level of comprehension. Visual and concrete examples have been identified as the most appropriate and effective forms of delivering sexuality education. The use of videos, slides, drawings, and role plays are all useful examples of strategies useful in this area (Baylis 1992). It is also vitally important to collaborate with people with an intellectual disability themselves to ensure that the sexuality education delivered, meets the needs and expectations of the individual or group that it is intended for (Mirfin-Veitch, Bray, Walker and Moore, in preparation). This point is supported by Huntley and Benner (1993) who asserted that client opinions and feelings regarding sexuality issues could provide vital information for effective programming.

Lindsay, Bellshaw, Culross, Staines and Michie (1992) presented research findings that supported the benefits of sexuality education for adults with an intellectual disability. Their research was designed in an attempt to determine whether sex education results in long-term improvements in knowledge gain for such adults. Lindsay et al found that adults who had participated in a nine-month sex education programme demonstrated significant knowledge gains after being evaluated directly following the completion of the programme. These gains were found to have been sustained when the adults were evaluated three months later.

Finally, sexuality education is most effective if it is presented by experienced sexuality educators who are aware of, and responsive to, the specific learning needs of adults who have an intellectual disability. Mirfin-Veitch, Bray, Moore, Walker and Ross (2000) found that community based health educators, including sexuality educators, were not always skilled at meeting the specific needs of such adults. Furthermore, when educators had not considered the specific education strategies that might be useful to adults with an intellectual disability, or developed an education session that took such issues into consideration, education sessions were not always effective. This finding emphasises the importance for community based health (and sexuality educators) to be trained to provide effective education to adults with an intellectual disability.

Implications for service development in the area of intimate and sexual relationships

This review has illustrated the considerable disadvantage that adults with an intellectual disability experience as they attempt to pursue their right to express their sexuality and to lead sexual lives. Implications for service development in the area of intimate and sexual relationships are outlined below.

- Adults with an intellectual disability must be seen as sexual beings by families, service providers, and members of the community.

- Sexuality does not refer simply to sex. Acknowledgement must be made of the wide and diverse range of relationships that adults engage in and that they may need support to pursue such relationships.

- Attention must be paid to the need for adults with an intellectual disability to have access to safe environments in which they can talk about sex and sexuality. Both men and women with an intellectual disability have important things to say about intimate and sexual relationships.

- Families need to be encouraged to see sexuality as a typical part of their adult family members' life. They should also have access to support or advice in this area , and be encouraged to have input into sexuality education for adults with an intellectual disability.

- Intellectual disability services and direct care workers need to acknowledge the importance of this area and ensure that policy and practice reflect the needs of adults who wish to pursue intimate and/or sexual relationships.

- The high incidence of sexual abuse in the lives of adults who have an intellectual disability is unacceptable. Abuse must be treated seriously by service providers and appropriate actions and interventions put in place to eliminate abuse.

- The ability for adults with an intellectual disability to access appropriate and effective sexuality education is critical to their ability to achieve positive intimate or sexual relationships.

- Sexuality education should be proactive. Waiting until questions are asked or a "problem" occurs is not appropriate. Many adults with an intellectual disability have difficulty in articulating their need for knowledge and are at risk of significant disadvantage if sexuality education is not offered to them.

- Children and adults with an intellectual disability should receive the same opportunities for sexuality education as other children and adults.

- Sexuality education should be preceded by, or be accompanied by general information related to the development of positive relationships.

- Sexuality education should be provided by sexuality educators who are aware of, and responsive to, education strategies that are useful to adults with an intellectual disability.

References

Appleby Y. 1994. Out in the margins. *Disability and Society* 9(1): 19-32.

Bambury J, Wilton K, Boyd A. 1999. Effects of two experimental educational programs on the socio-sexual knowledge and attitudes of adults with mild intellectual disability. *Education and Training in Mental Retardation and Developmental Disabilities* 34(2): 207-11.

Baylis D. 1992. Giving women with an intellectual disability permission to be sexual. *Community Bulletin* 16(2): 15-7.

Becker W. 2001. Unpublished Masters Thesis: University of Otago

Brown H. 1994. 'An ordinary sexual life?': a review of the normalization principle as it applies to the sexual options of people with learning disabilities. *Disability and Society* 9 (2): 123-44.

Brown H, Stein J. 1997. Sexual abuse perpetrated by men with an intellectual disability: a comparative study. *Journal of Intellectual Disability Research* 41(3): 215-24.

Brown H, Thompson D. 1997. The ethics of research with men who have learning disabilities and abusive sexual behaviour: a minefield in a vacuum. *Disability and Society* 12(5): 695-707.

Cambridge P. 1996. Men with learning disabilities who have sex with men in public places: Mapping the needs of service users in South East London. *Journal of Intellectual Disability Research* 40(3): 241-51

Cambridge P. 1997. How far to gay? The politics of HIV in learning disability. *Disability and Society* 12(3): 427-53.

Cambridge P. 1999. Considerations for informing safer sex education work with men with learning disabilities. *British Journal of Learning Disabilities* 27(4): 123-6.

Cambridge P, Mellan B. 2000. Reconstructing the sexuality of men with learning disabilities: empirical evidence and theoretical interpretations of need. *Disability and Society*: 15(2): 293-311.

Furey E, Keharhahn M. 2000. What supervisors, managers, and executives know about the abuse of people with mental retardation. *Developmental Disabilities Bulletin* 28(2): 40-59.

Heyman B, Huckle S. 1995. Sexuality as a perceived hazard in the lives of adults with learning difficulties. *Disability and Society* 10(2): 139-55.

Huntley C, Benner S. 1993. Reducing barriers to sex education for adults with mental retardation. *Mental Retardation* 31(4): 215-20.

Jurkowski E, Amado A. 1993. Affection, love, intimacy and sexual relationships. In A. Novak (ed). *Friendships and community connections between people with and without developmental disabilities.* Baltimore: Paul H. Brookes Publishing Company.

Lindsay W, Bellshaw E, Culross G, Staines C, Michie A. 1992. Increases in knowledge following a course of sex education for people with an intellectual disability. *Journal of Intellectual Disability Research* 36: 531-9.

McCabe M, Schreck A. 1992. Melbourne: Psychology Research Centre, Deakin University.

McCarthy M. 1999. *Sexuality and women with learning disabilities*. London: Jessica Kingsley Publishers Ltd.

McCarthy M, Thompson D. 1996. Sexual abuse by design: an examination of the issue in learning disability services. *Disability and Society* 11(2): 205-17.

Melberg Schwier K. 1994. *Couples with an intellectual disability talk about living and loving.* Rockville, MD: Woodbine House.

Mirfin-Veitch B, Bray A, Moore T, Walker F, Ross N. 2000. *Promoting awareness of women's health: Health education with women with an intellectual disability.* Paper presented to the 11th World Congress of the International Association for the Scientific Study of Intellectual Disability (IASSID) "New Millennium: Research to Practice." Seattle, Washington, USA, August 1-6.

Mirfin-Veitch B, Bray A, Moore T, Walker F. 2000. *Paper in preparation.*

Pendler B. 1993. Opening Pandora's Box: A parent's perspective on friendship and sexuality. In A Novak (ed). *Friendships and community connections between people with and without developmental disabilities.* Baltimore: Paul H. Brookes Publishing Company.

Slattery J. 2000. Family, Marriage, Friends and Work: This is my life. In R Traustadottir, K Johnson. *Women with an intellectual disability: Finding a place in the world.* London: Jessica Kingsley Publishers.

Sobsey D. 1994. Violence and abuse in the lives of people with disabilities: The end of the silent acceptance? Baltimore: Paul H Brookes Publishing Company.

Szollos A, McCabe M. 1995. The sexuality of people with mild intellectual disability: Perceptions of clients and caregivers. *Australia and New Zealand Journal of Developmental Disabilities* 20(3): 205-22.

Taking More Control of my Health: A Health Guide for Women. 2001. Dunedin: Donald Beasley Institute.

Thompson D, Clare I, Brown H. 1997. Not such an 'ordinary' relationship: the role of women support staff in relation to men with learning disabilities who have difficult sexual behaviour. *Disability and Society* 12(4): 573-92.

Wish J, McCombs K, Edmonson B. 1980. *The socio sexual knowledge and attitude test*. Chicago: Stoelting.

PLAIN LANGUAGE SUMMARY

Adults with an intellectual disability who are parents

Having children is one of the most rewarding and challenging parts of being an adult. In the past people with an intellectual disability have often been stopped from getting married or having children. Many people think that adults who have an intellectual disability should never have children because they would be unable to care for them properly. Other people think that if people with an intellectual disability have children that the children will also have disabilities. While many parents who have an intellectual disability may need special and long-term support to bring up their children, research has shown that they can be good parents.

We do not know exactly how many adults who have an intellectual disability are parents but most researchers agree that more of them are having children. Adults with an intellectual disability have talked about what having children means to them. Some adults see having children as part of being married. Adults with an intellectual disability sometimes spend a lot of time deciding whether or not to have children.

Research has shown that parents who have an intellectual disability often get their children removed from their care. For this reason a lot of research has looked at the issue of whether adults with an intellectual disability can be "good" parents. Some of the research says that some people with an intellectual disability can be good parents, while other researchers say that they will all have problems in some areas. Often it is hard for parents with an intellectual disability to meet other people's standards of what it means to be a good parent.

The most useful research about parenting by people with an intellectual disability describes the things that help adults to be good parents and the things that make it difficult for them. Some of the difficulties that parents face are caused by their intellectual disability, while others are caused by their experiences or the way other people treat them. Because adults with an intellectual disability have trouble learning it is sometimes hard for them to learn all the skills needed to be a parent. Research has shown, however, that adults can learn these skills when they receive support to do so. Support to learn parenting skills is more successful if it happens in parents' homes, and if the parents have made their own decisions about what they want to learn. Support services should also take into account the needs of the whole family. Parents with an intellectual disability themselves have said what sort of support services would be useful to them. First, they need to be supported to work out problems within their families without the fear that their children will be permanently removed from their care. Second, they need support which is private and carried out in their own home.

This review has shown that:

- parents who have an intellectual disability are a group of parents who face many barriers to keeping and raising their children
- many parents will need special training and support in the area of parenting in order to be good parents. This support may need to be ongoing

- intellectual disability services, family support services and other professionals need to be positive towards adults with an intellectual disability and avoid making assumptions about their ability to parent
- many parents with an intellectual disability avoid disability services. This makes it necessary for ordinary family support service staff to have special training in working with people with an intellectual disability
- intellectual disability service staff do not always have the skills to provide parenting support. Services need to make sure that they are able to meet the needs of parents with an intellectual disability.

ADULTS WITH AN INTELLECTUAL DISABILITY WHO ARE PARENTS

Introduction

(This review which focuses on parenting by adults with an intellectual disability is based on an earlier report written by Dr Anne Bray and, therefore, remains the intellectual property of the Donald Beasley Institute.)

Caring for and rearing children safely and well is one of the most rewarding **and** challenging tasks of adulthood. Many personal and societal factors interact to make this task easier or to pose enormous barriers to successful parenting. A parent who has a disability faces some additional hurdles to successful parenting and when that disability is one of cognition or learning, then parenting will be an even greater challenge. Parents who have such difficulties (labelled "intellectual disabilities" in this essay) may need special and long-term support in order to be adequate parents. Without such support the health and wellbeing of their children are "at risk", in terms of experiencing neglect or abuse. However, an assumption that such parents are automatically and forever inadequate as parents can result in discriminatory treatment by the law and state policies and in inadequacies in the provision of support to parents by generic family- and/or disability support services.

This component of the review of adult services will explore the research literature relating to parents who have an intellectual disability, examine the multiple barriers faced by adults with an intellectual disability who wish to be good parents, and suggest appropriate strategies for improving systems of support aimed to better support children and their parents' and to advance the wellbeing of families.

Historical overview: How has society dealt with these issues in the past?

In order to examine this critical issue in the lives of adults with intellectual issues it is necessary to outline how society has responded to parenting by adults who have an intellectual disability in the past. Societies have always identified individuals who differed significantly in their ability to fulfil the tasks expected of other members of that society of the same age and sex. Reactions to these differences varied across ancient societies, from killing to isolation, to protection, and even the accordance of special status. When it was recognised that some differences had their cause in some area of mental functioning, people who were mentally ill **or** mentally retarded were often viewed and treated in indistinguishable ways. Such confusion and ignorance is still seen today, even among the legal profession and in some statutes. For example, the previous Mental Health Act included "intellectual disability" as a type of "mental disorder". Many psychiatric hospitals in New Zealand used to admit patients who were mentally ill **and** patients who had an intellectual disability.

With the developing scientific knowledge about the principles of genetic inheritance and more understanding of the **differences** between mental illness and mental retardation, pressure grew in Western societies for the compulsory prevention of procreation by people labelled as "defective". A variety of societal measures were developed. During the

late 19th and early 20th centuries people with disabilities were increasingly isolated from society in large institutions within which there was strict segregation of the sexes.

Laws prohibiting marriage and providing for enforced sterilisation were common in most countries and states, therefore, stereotypes and prejudice were codified into law throughout common-law countries. The basic assumptions and errors on which such discriminatory laws were based led to the following argument:

> **Because** the causes of intellectual disability are found in genetic inheritance;
> **and** intellectual disability is a tragedy and a cost to society and must be prevented;
> **and** people with an intellectual disability do not have the same rights as other individuals to bodily integrity, and to procreate;
> **Therefore** the prevention of procreation by people with an intellectual disability will eliminate intellectual disability from society and is thus justifiable.

The ultimate implications of eugenics beliefs found their expression in the Holocaust, in which 250,000+ people with disabilities were murdered and many more forcibly sterilised (Sobsey, Donnellan and Wolbring 1994). Fifty years on, the eugenics movement may be largely an anachronism, but debate continues in many countries over the issue of sterilisation of people with an intellectual disability without their consent (Elkins and Anderson 1992). Advances in the natural sciences have showed the enormous variety of genetic and environmental factors which may affect cognitive abilities and functioning. While eugenic concerns may have abated, there are still widely held assumptions about the characteristics of people with an intellectual disability and their presumed inability to be "good enough" parents. There is a lack of appreciation of the range of capacity and individual differences among the group of people society labels as "intellectually disabled". All are presumed to be grossly incompetent. There is a ready tendency to assume that there is no possibility of people with an intellectual disability learning new skills and responding to educational and supportive services. Incompetence in parenting is still often seen as biologically determined and immutable.

What is the contemporary context for these issues?

An earlier review discussed in detail the issues related to defining intellectual disability. When discussing intellectual disability in parents, definitional issues need to be very carefully considered. The majority of people with an intellectual disability who become parents are those with milder degrees of intellectual disability, or difference from the defined norm. They may be identified as having an intellectual disability or they may not. They may meet the strict technical criteria of a particular definition or they may not. They may meet the criteria at one stage of their lives but not at another. They may meet the criteria when assessed today, but not next week, or when assessed by someone else, or with a different measuring instrument. Because of the stigma of a label of "intellectual disability" they often go to extraordinary lengths to hide their learning difficulties to pass as "normal". A label of "intellectual disability" is likely to result in increased control by others and curtailment of liberties, rights and independence in many areas.

Given these definitional issues and their implications, it is not possible to provide scientific measures of the numbers of these parents and where they are, with the resulting difficulty in planning and providing appropriate support services for them in their

parenting. Those parents who are identified are likely to be those who are experiencing parenting problems, and are therefore not representative of **all** parents who have an intellectual disability.

In New Zealand, a recent study provided an estimate of the prevalence of parents with an intellectual disability using a key informant method. The researchers surveyed a wide range of primary health, social services, and disability providers in Otago and Southland (Mirfin-Veitch, Bray, Williams, Clarkson and Belton 1999). Using a statistical estimation technique called capture-recapture, a prevalence rate was generated in this study of 2.51 families per 1000 families (ie, families in which at least one parent had an intellectual disability, based on a functional definition). Whitman and Accardo (1990) have concluded that:

> *the true prevalence of parents with mental (intellectual) disabilities is unknown and possibly unknowable (p 13).*

While accurate prevalence figures may be impossible to determine, there is strong evidence that such parents feature significantly in the caseloads of child protection and family support services, both in New Zealand and in other countries. For example, Mirfin-Veitch et al (1999) found that 41 percent of the children of those parents identified had been removed from their care. Over half of the parents were, however, still caring for children with minimal support. In an earlier American study, the percentage of children removed was 45 percent (Whitman, Graves and Accardo 1987). Research recently undertaken in two Sydney Children's Courts into 407 care and protection cases have found that 7 percent of these cases involved parents with an intellectual disability (McConnell and Llewellyn 2000).

In summary, the current situation in New Zealand and similar societies then appears to be as follows. Parents with an intellectual disability are a largely invisible group in terms of formal identification as a group. However, there is a growing recognition that they deserve greater attention in terms of their increasing numbers and the frequency with which they appear to provide less than adequate parenting for their children. At recent international meetings on this topic, social planners recognised the concept of "critical mass" in the current situation – "… a critical number is needed before the group and their needs become noticeable" – but they concluded that "because parents with an intellectual disability are an emerging population, it does not seem that critical mass status has been reached in any country" (Tymchuk, Llewellyn and Feldman 1999). This emerging recognition is reflected in the recency of social science research in the area, the majority of which has been published in the last decade.

What do we know about parenting by people who have an intellectual disability?

What adults with an intellectual disability have said about parenting

The discussion of "what we know about" adults with an intellectual disability will commence with personal accounts from parents who have an intellectual disability themselves.

Janice Slattery (2000) provided a personal account of her decision making processes regarding whether or not to try and have a baby. She said this:

> *Part of getting married was about having kids. We got married at 35 and I didn't want to rush into having kids. Then John and I talked about it and I wanted to find out if the child would be like me when I was a child. So we went to Family Planning and everything. And then eventually we got tested and we found that we had all the chromosomes so we could have a child. But I wanted to go to a genetic counselor. So John and I both went to see one. Mum came and helped me. I was 37 at the time and they said to me that because of my age and because of my disability it would probably be a 50/50 chance that it could be a Down's Syndrome child and that... It was a hard decision for us. And we came to the decision that we didn't want to put our child at risk of being teased at school like I was... We decided against it... And everyone was so proud of us that we went to a genetic counselor and to Family Planning because most couples rush into having kids... (p 99)*

Slattery identifies the issues that she and her partner took into account when deciding whether or not to have a baby. The complex process that they went through challenges the assumption that people with an intellectual disability do not consider the issues and implications associated with having children. Her personal reflections also indicate her own concerns about raising a child if it were to suffer the discrimination and prejudice that she did.

Christiane de Burg (2000) articulated her views on the experience of being a parent with an intellectual disability.

> *I know that there are other mothers with learning disabilities and that they have to cope alone too. But it would be good if they could get support with specific problems. Lots of women with learning disabilities want to have children, just like other women do. Some staff are positive about this, but most are negative. They always think that you will have problems* (p 237).

When asked what kind of support is useful to parents who have an intellectual disability de Burg had the following advice.

> *I think it is better to see people individually and at home, because it is more private. When I have problems I get my help at home and this creates another atmosphere. At centres it is not private and I would be worried that they don't have a real choice. But I know that children are sometimes in danger and so sometimes mothers have to be forced into things... I believe in a system where children would be taken into foster care temporarily, to give the women time to sort out their problems with their husbands. That would give the women time to recover and know that they had not lost their children forever* (p 238).

Research on parenting by adults who have an intellectual disability

One of the most famous early studies in child development research provides positive evidence as to parenting by women with an intellectual disability (Skeels 1966). Ironically, this aspect of the research has received virtually no comment, with the study results receiving fame in terms of their strong evidence for the effect of early environmental experiences on later child development. In this experimental study a group of very young children in an orphanage were divided into two groups at the mean age of 16 to 19 months. One group showed significantly delayed development and were sent to an institution for children and adults with an intellectual disability. At the institution, each child was assigned to the care of one of the women "inmates" ie, to a woman with an intellectual disability living in the institution. Eleven of these 13 children were later adopted. The other group of children, who were apparently developing relatively normally, remained in the orphanage. A follow-up of both groups of these children 21 years later showed surprising results. The children who had been parented by women with an intellectual disability in an institution had recovered from early delays in the first two years, had developed normally and were now leading normal adult lives. Those children who had remained in the orphanage showed increasing developmental delay in their early years and in adulthood showed low educational achievement and very few were employed. The love, close 1:1 attention, and stimulation provided by the "mentally retarded foster mothers" was sufficient to reverse early disadvantages and promote normal development in these young children.

Parents with an intellectual disability have received increasing attention from social scientists over the last decade, but this literature appears to have had little effect on law, policy and practice. As in all areas of research into the complexity of human development, there are no simple answers. Particularly when answers are sought as to the effects of one particular factor on the development of children, the answer of an honest social scientist must always be "It depends". What then can we conclude from research on child outcomes for children of parents with an intellectual disability?

Child outcomes

Children of parents with an intellectual disability appear to be more likely than children of other parents to experience an intellectual or other developmental disability themselves, but actual results from studies show a range of degree of risk. The risk is higher if both parents have an intellectual disability (Dowdney and Skuse 1993; Feldman 1986).

Earlier follow-up studies of adults showed a greater incidence of disability in their children than in the general population (Gillberg and Geijer-Karlsson 1983; Reed and Reed 1965). At the same time, it is important to stress that the majority of children born to parents with an intellectual disability do **not** have disabilities.

There are also methodological problems with available research (Dowdney and Skuse 1993; Espe-Sherwindt and Crable 1993; Tymchuk, Andron and Unger 1987). The samples of parents were not representative of the population of such parents, with limited samples identified from institutional records or records of child welfare or mental health services. There is no evidence that the incidence of intellectual disability due to organic

etiology is higher in these children than in the general population (Espe-Sherwindt and Crable 1993; Tymchuk et al 1987). All samples have been from lower socioeconomic groups, thus confounding the factors of parental intellectual disability and poverty (Tymchuk et al 1987). Poverty is correlated with many causes of disabilities in children.

A recent study which controlled for the effects of poverty (Keltner, Wise and Taylor 1999) found some evidence for an increased incidence of delay in the children of mothers with an intellectual disability at two years of age (42% vs. 12%), confirming findings of an earlier study (Feldman, Case, Towns and Betel 1985). These findings suggest that mothers with an intellectual disability and their children may be particularly vulnerable to the environmental strains related to poverty.

Outcomes for older children were also recently examined (Feldman and Walton-Allen 1997). All mothers with an intellectual disability were recruited through "mental retardation services" (a selective sample), while comparison mothers were recruited through community resource and drop-in centres in the same low-income neighbourhoods. The children of mothers with an intellectual disability had lower IQs, lower academic achievement and more behaviour problems than children in the comparison group.

The majority of studies on child development outcomes have focused on intellectual development and achievement. Two studies have noted a risk of poor adjustment or problem-behaviour in children with "normal IQs" who have a parent with an intellectual disability (Feldman and Walton-Allen 1997; O'Neill 1985) but there is a dearth of research detailing emotional and behavioural outcomes in children.

Although we can conclude that poorer developmental outcomes for children of parents with an intellectual disability are more likely than for other children, the more important questions for social science are "Which children?" and "Why do some children develop normally and some do not?" Child development theory is paying increasing attention to the concepts of "risk" and "resilience" to investigate and understand such questions. To study these issues it is helpful to undertake detailed, longitudinal studies which currently do not exist. Such studies also are time and context-bound in terms of their generalisability to contemporary society. Another method of study is to ask the children themselves when they are adults about their life experiences of being reared by a parent(s) with an intellectual disability.

Booth and Booth (1997) carried out a series of in-depth interviews with 30 adults who had one or more parents with an intellectual disability. Fifteen of these adults also had an intellectual disability themselves. While the stories of these adults' lives show that their lives had not been easy and many had disabilities or mental health problems, it is impossible to separate the effects of parenting per se from the multiple effects of other confounding factors, particularly poverty and deprivation. When examining the achievement of adult identities, Booth and Booth concluded that those adult children without an intellectual disability

> *experienced no problems of a type or magnitude sufficient to distinguish them from other people coming from the same socioeconomic background (p 35).*

They identified three types of protective factors which increased the children's resilience to the developmental risks they faced: dispositional attributes of the child, such as sociability and an internal locus of control; affectional ties within the family; and external support systems that reward competence and determination, and provide a guiding, belief system to the developing individual (p 36). As one person in their study said, what mattered most as a child was: *the fact that we were living with people we loved"* (p 38).

Parental competence

Poorer outcomes for children have frequently been attributed directly to parental incompetence, which in turn has been seen as caused by intellectual disability in a parent, usually the mother. As with research on child outcomes, there are problems in looking for simple answers to these complex questions. One of the most difficult issues is that parental competence or adequacy is seldom defined, either in the research or in the processes used by officials or agencies to identify parental incompetence (Dowdney and Skuse 1993; Tymchuk et al 1987; Young, Young and Ford 1997). The criteria of parenting competence vary from study to study including: physical care, need for supports; child outcomes; referral to child protection agencies.

These differing definitions of parenting competence also result in the use of a variety of measures. Studies are also limited by the same methodological problems noted in child outcome research. There are therefore conflicting conclusions presented from studies assessing the quality of parenting provided by parents with an intellectual disability (Dowdney and Skuse 1993). Some studies conclude that most parents do reasonably well, while some researchers suggest that all parents are incompetent to varying degrees (Tymchuk et al 1987).

For the parents themselves the lack of a consensus on what is meant by "adequate parenting" is particularly problematic, as they are likely to be judged by different standards by each of the different professionals with whom they come in contact, and will be expected to comply with all these different expectations (Espe-Sherwindt and Crable 1993).

What general conclusions can be supported by the research evidence, while acknowledging its limitations? Firstly, there is no clear relationship between parental competence and intelligence, as measured by IQ, although mothers with an IQ below 50 may often have greater difficulties (Budd and Greenspan 1985; Feldman 1986; Gath 1988; Zetlin, Weisner, Gallimore 1985). IQ should therefore never be used as a measure of current competence or a predictor of future competence.

There is also evidence from studies in a variety of countries that parents with an intellectual disability may be more likely than other parents to have their children removed from their care due to allegations of neglect or abuse (Dowdney and Skuse 1993; Gillberg and Geijer-Karlsson 1983; Whitman and Accardo 1990). However, due to unrepresentative sampling and methodological problems in many studies, it is not possible to give an accurate figure of the extent of neglect and/or abuse among parents with an intellectual disability. There are also other factors affecting child removal decisions, which will be examined in more detail in the next section.

With regard to sexual abuse, there is considerable evidence that children and adults with an intellectual disability are at higher risk for sexual abuse themselves (Sobsey 1994), but there is no accurate evidence as to the risk of sexual abuse of their children by parents with an intellectual disability.

The most useful evidence from research describes particular factors which help or hinder parental competence in this group of parents. Some of their difficulties can be related to their cognitive limitations themselves while others are due to their life experiences and the way other people treat them because of their disability. However, most of the factors are shared by other parents who live in poverty and experience numerous and ongoing environmental stressors in their lives. These factors are also predictive of poor parenting, neglect or abuse in other families.

By definition, parents with an intellectual disability experience difficulties in learning, particularly in areas involving abstract concepts or complex reasoning. They also have difficulties generalising what they learn to other problems, places, or situations (Booth and Booth 1993; Young et al 1997). Solving problems or making decisions can be difficult for them, particularly in crises or unfamiliar situations (Espe-Sherwindt and Crable 1993; Tymchuk, Yokota and Rahbar 1990) although this is also affected by the limited experiences they may have had in their lives (Llewellyn 1997). Poor communication and social skills are also likely to be due to an interaction of learning difficulties and lack of experience (Espe-Sherwindt and Crable 1993; Glaun and Brown 1999). Similarly, a lack of understanding of child development and limited basic childcare skills (Feldman 1994) cannot be attributed solely to intellectual disability, but are affected by access to appropriate educational and learning opportunities.

Studies have also identified the negative affects on parenting competence when the parent with an intellectual disability has additional health or functioning problems, such as alcoholism, health problems, personality disorder, or mental illness (Glaun and Brown 1999; Llewellyn 1990; Tymchuk et al 1987; Young et al 1997).

Research has identified family factors that may make parenting more difficult for parents with an intellectual disability, although these factors are not limited to this group of parents. They include: single parenthood (Dowdney and Skuse 1993; Glaun and Brown 1999), disability or behavioural problems in the child (Dowdney and Skuse 1993; Glaun and Brown 1999), partner relationships (Dowdney and Skuse 1993; Llewellyn 1995; Tymchuk et al 1987;) the challenges of older children and adolescents (Dowdney and Skuse 1993), family size (Dowdney and Skuse 1993; Glaun and Brown 1999; Llewellyn 1990; Tymchuk et al 1987) family spacing (Zetlin et al 1985), and partner characteristics and behaviour (Dowdney and Skuse 1993; Gath 1988; Llewellyn 1990; Gath 1996; Young et al 1997).

People with an intellectual disability often have very different life experiences to other people, with resulting effects on their parenting competence. In addition to the experience of institutionalisation for many adults in the past (Budd and Greenspan 1985; Gath 1988; Llewellyn 1990; Tymchuk et al 1990), a significant number of parents with an intellectual disability have experienced severe deprivation and/or abuse in their own childhoods (Dowdney and Skuse 1993; Glaun and Brown 1999; Llewellyn 1990). These experiences have resulted in a serious lack of any appropriate role models from which to learn parenting skills (Booth and Booth 1994; Booth and Booth 1993; Gath 1988; Glaun and

Brown 1999; Llewellyn 1997; Young et al 1997). Even when these adults have been raised in the community within a non-abusive family, they may receive a very poor preparation for adulthood (Booth and Booth 1994) having been taught to be dependent (Booth and Booth 1994; Llewellyn 1997; Young et al 1997) and compliant, looking to others for directions and rewards. As adults they often have low self esteem (Espe-Sherwindt and Crable 1993; Feldman, Case, Rincover, Towns and Betel 1989) and are socially isolated, with few friends (Booth and Booth 1993; Dowdney and Skuse 1993; Llewellyn 1997; Llewellyn 1995). It is not surprising that parents with an intellectual disability often lack adequate social and family support (Booth and Booth 1994; Booth and Booth 1993; Dowdney and Skuse 1993; Glaun and Brown 1999; Llewellyn 1995; Llewellyn, McConnell, Cant and Westbrook 1999; Tucker and Johnson 1989).

The stigma of intellectual disability itself can often result in experiences of victimisation and harassment (Booth and Booth 1993) and exclusion from mainstream society (Booth and Booth 1993; Booth and Booth 1994). In reaction to these experiences, parents with an intellectual disability usually put enormous efforts into "passing as normal" (Edgerton 1967) shunning or refusing help from social agencies (Glaun and Brown 1999) and trying to avoid what are often high levels of surveillance (Booth and Booth 1994) and multiple agency involvement in their lives (Dowdney and Skuse 1993; Llewellyn 1997). Their experiences with some professionals are often negative, with many professionals displaying preconceived and judgmental attitudes towards them (Glaun and Brown 1999; Gath 1996).

As Keltner et al (1999) point out:

> *The powerful stigma of mental retardation forces many mothers with intellectual limitations to hide behind the label of being uncooperative or appearing disinterested rather than reveal the intellectual limitations (p 55).*

The vast majority of parents with an intellectual disability live in poverty (Booth and Booth 1993; Booth and Booth 1994; Dowdney and Skuse 1993; Glaun and Brown 1999; Llewellyn 1990; Tymchuk et al 1987) and many of the difficulties they face in being "good enough" parents are directly caused or compounded by the multiple negative factors associated with poverty. Unemployment (Dowdney and Skuse 1993; Glaun and Brown 1999), poor housing (Gath 1996; Booth and Booth 1993), lack of holidays or respite (Booth and Booth 1993), no phone or immediate transport (Booth and Booth 1993), lack of practical support (Llewellyn et al 1999), and lack of stability in family and living circumstances (Glaun and Brown 1999) – are all environmental strains faced by poor people trying to raise their children.

This review of the research literature relating to parents who have an intellectual disability highlights that competence cannot be, (and should never be), judged or predicted on a simple measure or label of an intellectual disability in a parent. Raising children involves far more than a particular parent's knowledge, practical skills, and abstract reasoning ability. From their unique research which explored the actual experiences of parents with an intellectual disability themselves, British researchers Booth and Booth (1993) conclude:

> *Parental competence is not just a matter of possessing adequate parenting skills.*
> *It is an attributed status which owes as much to the decisions of professionals as*

to the behaviour of parents. It is situationally determined by the quality or poverty of the environment in which people live. Competence too is socially constructed in terms of the normative standards and evaluative judgements enforced by the wider society, official agencies and their front-line representatives (p 16).

Strategies to improve parenting

As awareness grew during the 1980s that some parents with an intellectual disability may lack the skills to provide adequate care for their children, parent training programmes to teach these skills were developed, particularly in USA and Canada. These training programmes were also driven by the strong evidence in the psychological and educational literature that people with an intellectual disability, even severe disabilities, could learn a variety of skills. Programmes have usually been based on behavioural principles and methods, have focused almost exclusively on mothers (Booth and Booth 1994), and have usually been based with demonstration or research projects (Llewellyn and Brigden 1995).

Parent training programmes have been provided, with varying degrees of success in the content areas of: basic child care skills (Keltner, Wise and Taylor 1999) safety in the home skills (Keltner et al 1999; Tymchuk, Hamada, Andron and Anderson 1993) child behaviour management (Dowdney and Skuse 1993), and mother-child interaction or play skills (Dowdney and Skuse 1993; Feldman, Sparks and Case 1993; Feldman, Towns, Betel, Case, Rincover and Rubino 1986; Keltner et al 1999; Peterson, Robinson and Littman 1983; Slater 1986). In some studies, training in mother-child interaction with very young children has been shown to have demonstrable benefits in child outcomes (Feldman, Sparks and Case 1993). Training parents to change abusive or neglectful parenting has had limited success (Dowdney and Skuse 1993).

While the success of such programmes has been demonstrated in special projects, researchers and service providers have called for much wider provision of specially designed parent-training programmes for parents with an intellectual disability. Traditional parent-training programmes are usually inappropriate for these parents because of their special learning needs, and they may feel uncomfortable within the particular settings and people who attend generic programmes or parenting groups (Booth and Booth 1998). In comparison to other generic parent training programmes, programmes for parents with an intellectual disability may need to be more elaborative, more directive, and of longer duration (Budd and Greenspan 1985). Training needs to use highly concrete approaches and methods to ensure generalisation of learning, and is more successful when carried out in the home (Llewellyn and Brigden 1995) and the goals of training are negotiated with the parents (Dowdney and Skuse 1993). The content areas which have been identified as areas of great need include: basic childcare, health and safety (Dowdney and Skuse 1993; Feldman et al 1993; Feldman and Case 1999); basic skills (Hur 1997); problem-solving skills (Lynch and Backley 1989; Mirfin-Veitch et al 1999); decision-making processes in real life (Tymchuk et al 1990); skills in developing friendships (Booth and Booth 1993); self-esteem and assertiveness skills (Espe-Sherwindt and Kerlin 1990; McConnell, Llewellyn and Bye 1997); managing money (Mirfin-Veitch et al 1999); and behaviour management skills (Mirfin-Veitch et al 1999).

Parent training programmes are now recognised as only one component of essential support services for parents with an intellectual disability. With growing evidence from research which has investigated the parents' actual daily experiences and perceptions of their own needs, a much broader approach to supporting these families is essential. Booth and Booth (1996) have criticised what they perceive to be a narrow focus on short-term training in specific skills and reactive responses to crises. They contend such an approach is based on a 'deficit model' of service delivery which is resource-led and crisis-driven, focuses primarily on people's problems and failings, and puts the professional in control.

The service models proposed by researchers, service providers and parents themselves emphasise the need to move away from a 'deficit model' of services. The broad characteristics of support services proposed for parents with an intellectual disability are highly similar to contemporary principles underlying support services for other families (Munford and Sanders 1999). Services should build on parental strengths rather than focussing on limitations (Spencer 1998), and promote rather than inhibit parental competence (Booth and Booth 1993; Booth and Booth 1996; Espe-Sherwindt and Crable 1993) by recognising and supporting the resourcefulness of the parents and the wider family (Zetlin et al 1985). Parents' own decision-making abilities and self-realisation should be enhanced (Brechin and Swain 1988) and all supports should focus on empowering rather than supplanting families (McConnell, Llewellyn and Bye 1997).

In line with developments in other family services, professionals and support workers should work in partnership with parents (Booth and Booth 1996; Espe-Sherwindt and Kerlin 1990; Spencer 1998) and endeavour to develop trusting relationships (Espe-Sherwindt and Crable 1993; Tymchuk 1999). The goals for supportive services for each family should be based on and responsible to the views and priorities of the parents themselves (Brechin and Swain 1988; Espe-Sherwindt and Crable 1993; Llewellyn 1997; Llewellyn 1995; Tymchuk 1999). Finally, there is wide agreement that support services must be designed in ways which are proactive rather than reactive (Ely, Wilson and Phillips 1998; McConnell et al 1997; Tymchuk 1999) preferably beginning prior to the birth of the child (Ely, Wilson and Phillips 1998; Tymchuk 1999).

The support needs of parents who have an intellectual disability

In addition to a move towards recognised "best practice" models of family support, the research literature also recognises that these parents do have special needs related to their intellectual disability. Therefore services need to be either specially designed or adapted to take account of these needs.

Firstly, parents themselves need to know about these services and how to access them, rather than being reliant on someone else to refer them when a crisis occurs. Therefore services need to be advertised and promoted in a way which is accessible to these parents (Ely et al 1998) but which is not stigmatising. Given the problems with the definition and stigma of intellectual disability, it is also important that criteria for eligibility to access support are broad and non-stigmatising (Ely et al 1998).

Support workers and professionals working with these parents should have some specialised training and supervision to ensure that they are sensitive and responsive to the difficulties and barriers faced by parents because of their intellectual disability (Ely et al

1998; Lynch and Blackley 1989; Spencer 1998). Support services will also need to be long-term (Feldman et al 1989; Mirfin-Veitch et al 1999) intensive and individualised (Feldman and Walton-Allen 1997; Llewellyn et al 1997), with additional help needed in particular periods of family crisis or parenting difficulties.

As intellectual disability is a difficulty in learning, one of the important roles of support workers will be an educative one (Llewellyn et al 1997), ensuring that all aspects of support are provided at a level that the parent understands (McConnell et al 1997) and that parents are supported to learn in their own time and their own way as adult learners (Brechin and Swain 1988).

At a broader level, support services must take account of the realities of these families' lives and the enormous environmental strains (Llewellyn 1995; Tucker and Johnson 1989) placed on them by the multiple effects of poverty. Services should therefore be family-centered rather than focusing only on the parent or the child (Llewellyn et al 1997). Most services should be provided in-home (Mirfin-Veitch et al 1999) rather than expecting parents to travel to services. Professionals and support workers should understand and work within family relationships and preferred family styles (Zeitlin et al 1985) rather than imposing white, middle-class standards on families of different cultures and/or socioeconomic circumstances. This type of support builds on existing informal support systems within the family and extended family system (McConnell et al 1997) but remains sensitive to the possibility of family involvement which inhibits competence in the disabled parent (Llewellyn et al 1999; Tucker and Johnson 1989).

Without systematic efforts to alleviate the poverty in which many of these families exist, by ensuring families can access the resources they need, positive outcomes for these families will be limited. A recent action research project conducted by Booth and Booth (1998) in the United Kingdom has shown how essential it is for parents with an intellectual disability to have access to an on-going advocacy service to help:

> *to reduce the environmental pressures that undermine their ability to cope (p 63).*

As shown in these families' stories, one environmental pressure on many families that should be reduced is the number of different workers and agencies involved in the family.

Finally, the research highlights a number of broader policy issues which need urgent attention if parents with an intellectual disability are to be adequately supported. Broader social and structural issues must be addressed, including the provision of adequate funding for a comprehensive, long-term system of services (Ely et al 1998) and more effective inter-agency collaboration and integration of services (Espe-Sherwindt and Kerlin 1990; Llewellyn et al 1996). Current child protection services in most countries are not organised, trained or funded to provide adequate help to these parents over the long term (Llewellyn 1995b). In many Western countries over the last two decades, increasing poverty has resulted in reduced services, increased scrutiny and disregard by government agencies (Tymchuk 1999). Within the wider group of families in need, these families remain largely invisible and unserved.

There are also difficult ethical and practical issues which deserve wider debate and research attention. How should the interests of children and the interests of parents be appropriately and successfully balanced? Should the focus be on developing separate,

specialised services for these families, or adapting and extending generic family support services?

Implications for services designed to support parents who have an intellectual disability

The information presented in this review supports a general conclusion that parents with an intellectual disability in New Zealand are a significant but largely invisible group who face very difficult challenges in keeping and raising their children. The situation in New Zealand is strikingly similar to other Western, common law countries. There is a huge gap between what we know about parents' needs and success factors in support services (based on available research) and what actually happens to many parents. Implications for supports and services to this group of parents include:

- parents who have an intellectual disability are a group of parents whose primary disability is compounded by multiple barriers to keeping and raising their children successfully. Changes are needed at every system and practice level, particularly the education of every professional with whom they may come in contact. But changing attitudes is only one component of needed change. Many parents with an intellectual disability do need special training and support

- many parents who have an intellectual disability avoid or reject disability services because of the stigma involved. This makes it necessary to provide additional training to staff, and special services **within** generic services to parents

- intellectual disability support services in New Zealand typically provide services to people with a greater degree of disability than most people who become parents. Many of their staff do not have any professional training or even any training in the area of intellectual disability. It is important that whoever is responsible for planning and providing educational and support services to these families has the appropriate values, attitudes, knowledge and skills for the job. Staff and volunteers also need professional supervision and support in what is a very challenging and sometimes frustrating task, involving a number of practical and ethical dilemmas

- the examination of this topic also highlights the glaring need for sociolegal research which documents, evaluates and follows up the process and outcomes of child protection systems for children and parents.

References

Booth W, Booth T. 1998. *Advocacy for Parents with Learning Difficulties: Developing Advocacy Support.* Brighton, U.K: Pavilion Publishing.

Booth T, Booth W. 1997. *Exceptional childhoods, exceptional children. Growing up with parents who have learning difficulties.* London, UK: Family Policy Studies Centre.

Booth T, Booth W. 1996. Supported parenting for people with learning difficulties: Lessons from Wisconsin. *Representing Children* 9(2): 99-107.

Booth T, Booth W. 1994. Training and support for parents with learning difficulties: A digest of the research literature. *Journal of Practical Approaches to Developmental Handicap* 18(2): 10-14.

Booth T, Booth W. 1993. Learning the hard way: Practice issues in supporting parents with learning difficulties. *Social Work and Social Sciences Review* 4(2): 148-62.

Brechin A, Swain J. 1988. Professional/client relationships: Creating a 'working alliance' with people with learning difficulties. *Disability, Handicap and Society* 3(3): 213-26.

Budd KS, Greenspan S. 1985. Parameters of successful and unsuccessful interventions with parents who are mentally retarded. *Mental Retardation* 23(6): 269-73.

de Burg C with McCarthy M, van Hove G. 2000. My story. In D Atkinson, M McCarthy, J Walmsley, M Cooper, S Rolph, S Apsis, P Barette, M Coventry, G Ferris. *Good times, Bad times: women with learning difficulties telling their stories.* London: BILD.

Dowdney L, Skuse D. 1993. Parenting provided by adults with mental retardation. *Journal of Child Psychology and Psychiatry* 34(1): 25.

Edgerton RB. 1967. *The Cloak of Competence.* Berkeley: University of California Press.

Elkins TE, Anderson HF. 1992. Sterilization of Persons with Mental Retardation. *Journal of the Association for Persons with Severe Handicaps* 17(1): 19-26.

Ely E, Wilson C, Phillips E. 1998. Issues around service provision for parents with intellectual disability, *Interaction* 11(3): 7-13.

Espe-Sherwindt M, Crable S. 1993. Parents with mental retardation: moving beyond the myths. *Topics in Early Childhood Special Education* 13(2): 154-74.

Espe-Sherwindt M, Kerlin SL. 1990. Early intervention with parents with mental retardation: Do we empower or impair? *Infants and Young Children* 2(4): 21-8.

Feldman M, Case L. 1999. Teaching child-care and safety skills to parents with an intellectual disability through self-learning. *Journal of Intellectual and Developmental Disability* 24(1): 27-44.

Feldman MA, Walton-Allen N. 1997. Effects of maternal mental retardation and poverty on intellectual, academic, and behavioral status of school aged children. *American Journal on Mental Retardation* 101(4): 352-64.

Feldman MA. 1994. Parents with an intellectual disability. *Network* 4(1): 41-7.

Feldman MA, Sparks B, Case L. 1993. Effectiveness of home-based early intervention on the language development of children of mothers with mental retardation. *Research in Developmental Disabilities* 14: 387-408.

Feldman MA, Case L, Rincover A, Towns F, Betel J. 1989. Parent education Project III: Increasing affection and responsivity in developmentally handicapped mothers: Component analyses, generalization and effects on child language. *Journal of Applied Behavior Analysis* 22: 211-22.

Feldman MA, Towns F, Betel J, Case L, Rincover A, Rubino CA. 1986. Parent Education Project II: Increasing stimulating interactions of developmentally handicapped mothers. *Journal of Applied Behavior Analysis* 19: 23-37.

Feldman MA. 1986. Research on parenting by mentally retarded persons. *Psychiatric Clinics of North America* 9(4): 777-96.

Feldman MA, Case L, Towns F, Betel J. 1985. Parent and education project I: development and nurturance of children of mentally retarded parents. *American Journal of Mental Deficiency* 90(3): 253-58.

Gath A. 1996. Enhancing the parenting skills of people with a learning disability. In P Gropfert (ed). *(Title unknown)*: 244-50. Cambridge: Cambridge University Press.

Gath A. 1988. Mentally handicapped people as parents: Is mental retardation a bar to adequate parenting? *Journal of Child Psychology and Psychiatry* 29(6): 739-44.

Gillberg C, Geijer-Karlsson M. 1983. Children born to mentally retarded women: a 1-21 year follow-up of 41 cases. *Psychological Medicine* 13*:* 891-94.

Glaun D, Brown P. 1999. Motherhood, intellectual disability and child protection: characteristics of a court sample. *Journal of Intellectual and Developmental Disability* 24(1): 95-105.

Hur J. 1997. Review of research on parent training for parents with intellectual disability: methodological issues. *International Journal of Disability, Development and Education,* 44(2): 147-62.

Keltner B, Wise L, Taylor G. 1999. Mothers with intellectual limitations and their 2-year-old children's developmental outcomes. *Journal of Intellectual and Developmental Disability* 24(1): 45-7.

Llewellyn G, McConnell D, Cant R, Westbrook M. 1999. Support networks of mothers with an intellectual disability: An exploratory study. *Journal of Intellectual and Developmental Disability* 24(1): 7-26.

Llewellyn G. 1997. Parents with intellectual disability learning to parent: the role of experience and informal learning. *International Journal of Disability, Development and Education* 44(3): 243-61.

Llewellyn G, Bye R, McConnell D. 1997. Parents with intellectual disability and mainstream family agencies. *International Journal of Practical Approaches to Disability* 21(3): 9-13.

Llewellyn G, McConnell D, Bye R. 1996. *Support and services required by parents with intellectual disability.* Australia: Family Support and Services Project. Faculty of Health Sciences, University of Sydney.

Llewellyn G. 1995. Community services for parents with intellectual disability: specialist or generic? *Social Policy and the Challenges of Social Change Proceedings and the National Social Policy Conference.* Sydney, 5-7 July 1995, Volume 1, Saunders P, Shower S. (eds).

Llewellyn G. 1995. Relationships and social support: Views of parents with mental retardation/intellectual disability. *Mental Retardation* 33(6): 349-63.

Llewellyn G, Brigden D. 1995. Factors affecting service provision to parents with intellectual disability: An exploratory study. *Australia and New Zealand Journal of Developmental Disabilities* 20(2): 97-112.

Llewellyn G. 1990. People with intellectual disability as parents: Perspectives from the professional literature. *Australia and New Zealand Journal of Developmental Disabilities* 16(4): 369-80.

Lynch EW, Backley S. 1989. Serving young children whose parents are mentally retarded. *Infants and Young Children* 1(3): 26-38.

McConnell D, Llewellyn G, Ferronato L. 2000. *Parents with a disability and the NSW children's court.* Sydney: University of Sydney.

McConnell D, Llewellyn G, Bye R. 1997. Providing services for parents with intellectual disability: Parent needs and service constraints. *Journal of Intellectual and Developmental Disability* 22 (1): 5-17.

Mirfin-Veitch B, Bray A, Williams S, Clarkson J, Belton A. 1999. Supporting parents with an intellectual disability. *New Zealand Journal of Disability Studies* 6: 60-74.

Munford R, Sanders J. 1999. *Supporting Families.* Palmerston North: Dunmore Press.

O'Neill AM. 1985. Normal and bright children of mentally retarded parents: The Huck Finn syndrome. *Child Psychiatry and Human Development* 15(4) 255-68.

Peterson SL, Robinson EA, Littman I. 1983. Parent-child interaction training for parents with a history of mental retardation. *Applied Research in Mental Retardation* 4: 329-42.

Reed EW, Reed SC. 1965. *Mental Retardation: A Family Study.* Philadelphia: WB Saunders.

Skeels HM. 1966. *Adult status of children with contrasting early life experiences: a follow up study.* Chicago: Society for Research in Child Development.

Slater MA. 1986. Modification of mother-child interaction processes in families with children at-risk for mental retardation. *American Journal of Mental Deficiency* 91(3): 257-67.

Slattery J with Johnson K. 2000. Family, Marriage, Friends and work: This is my life. In R Traustadottir and K Johnson (eds). *Women with an intellectual disability: Finding a place in the world.* London: Jessica Kingsley Publishers.

Sobsey D. 1994. *Violence and abuse in the lives of people with disabilities. The end of silent acceptance?:* Baltimore. Paul H Brookes Publishing Co.

Sobsey D, Donnellan A, Wolbring G. 1994. Reflections on the Holocaust: Where did it begin and has it really ended? *Developmental Disabilities Bulletin* 22(2): 121-35.

Spencer M. 1998. Mums and Dads, doing the best for their kids – against the odds. *Interaction* 11(4): 8-13.

Tucker MB, Johnson O. 1989. Competence Promoting vs Competence Inhibiting Social Support for Mentally Retarded Mothers. *Human Organisation* 48(2): 95-107.

Tymchuk A. 1999. Moving towards integration of service provision for parents with an intellectual disability. *Journal of Intellectual and Developmental Disability* 24(1): 59-74.

Tymchuk A, Llewellyn G, Feldman M. 1999. Parenting by persons with an intellectual disability: A timely international perspective. *Journal of Intellectual and Developmental Disability* 24(1): 3-6.

Tymchuk A, Hamada D, Andron L, Anderson S. 1993. Training with mothers who are mentally retarded to make their homes safe: a replication. *Journal of Practical Approaches to Developmental Handicap* 17(2): 9-15.

Tymchuk A, Yokota A, Rahbar B. 1990. Decision-making abilities of mothers with mental retardation. *Research in Developmental Disabilities* 11(1): 97-109.

Tymchuk AJ, Andron L, Unger O. 1987. Parents with mental handicaps and adequate child care – a review. *Mental Handicap* 15: 49-54.

Whitman B, Accardo P. 1990. *When a Parent is Mentally Retarded.* Baltimore: Paul H. Brookes Publishing Company.

Whitman B, Graves B, Accardo P. 1987. Mentally retarded parents in the community: Identification method and needs assessment survey. *American Journal of Mental Deficiency* 91(6): 636-8.

Young S, Young B, Ford D. 1997. Parents with a learning disability: research issues and informed practice. *Disability and Society* 12(1): 57-68.

Zetlin AG, Weisner TS, Gallimore R. 1985. Diversity, shared functioning, and the role of benefactors: A study of parenting by retarded persons. In T Thurman (ed). *Children of Handicapped Parents.*69-95. N.Y: Academic Press.