

JOURNEYS



of

EXCLUSION

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The information in this report can be used to further knowledge and services for people with disabilities and their families. Any photocopying of parts of the document should include acknowledgement of the source of the information and the date of publication

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ACRONYMNS & ABBREVIATIONS

AAMR	-----	American Association on Mental Retardation
ABS	-----	Australian Bureau of Statistics
AIHW	-----	Australian Institute of Health and Wellbeing
CLA	-----	Community Living Association
CLP	-----	Community Living Program
CMC	-----	Crime and Misconduct Commission
DCS	-----	Department of Child Safety
DSQ	-----	Disability Services Queensland
ID	-----	Intellectual Disability
INCH	-----	Inner Northern Community Housing

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THE JOURNEYS OF EXCLUSION PROJECT

This research project was guided by a reference group consisting of members from Community Living Association Inc (CLA), At Risk Resource and Outreach Service (ARROS), Community Resource Unit (CRU), and the Office of the Public Advocate, with input from the University of Queensland School of Social Work and Applied Human Services. The purpose of the reference group has been to provide guidance, expertise and direction to the research worker.

Background

Community Living Program (CLP) was incorporated as a community agency in 1989, with a commitment to work with people with an intellectual disability. Shortly after their establishment as a service, CLP workers began to receive referrals of young people with an intellectual disability who were homeless. These young people had often been in the care of the state, had suffered serious exploitation in the community, and had had contact with the criminal justice and correction and/or mental health systems.

CLP therefore began a number of projects which led to the establishment of Women With Intellectual Disability (WWILD) Sexual Assault/Prevention Service, ARROS Homeless Outreach Service and WWILD Victims of Crime Service. CLP has undertaken a number of other initiatives to address the difficulties people with ID experience in the mental health, criminal justice and correction systems.

One common feature of many of the homeless people with an intellectual disability who have come in contact with CLP, and later with ARROS, has been an experience of out-of-home care or some other breakdown of natural family support. The current project is therefore a continuation of CLA's long-term interest in an extremely marginalised group of young people with ID who have experienced family breakdown and lack of supportive relationships.

Research Context of the Project

Over the last decade the Community Living Association has engaged with a variety of community partners to carry out research that highlights the disadvantages experienced by people with an intellectual disability. These research projects include:

- Falling Through the Gaps; From Understanding to Action – A discussion paper on responses to people with an intellectual disability who are considered to be at “risk” or are displaying “difficult behaviours” (Spencer & Ray, 1992).
- ARROS Pilot Project Final Report – a report on the findings and outcomes of piloting the service model proposed in the YAR<>MID research (Drew & Coffey, 1997).
- VOICES: People with an intellectual disability and the Criminal Justice System (Sewell, 1998).
- I Need to Sort my Head Out - Mental Health and Well Being in the lives of people with a learning difficulty (McDonald, 2002).

Community Living Association Inc manages the following services:

- Community Living Program – community access service for people with an intellectual disability.
- At Risk Research and Outreach Service – an outreach service to homeless young people with an intellectual disability.
- Village Housing – an intentional housing venture for people with and without an I.D.
- Reconnect – a service for young people (and their families) who are at risk of homelessness or early school leaving.
- Youth Support Co-ordinator – a service in high schools aimed at school retention and prevention of family breakdown and early school leaving.

CLA manages ongoing research projects into the situation of homeless people with an ID, people with a dual diagnosis of ID and mental health issues, and people with an ID who have experienced the correction and criminal justice systems.

CLA has also supported the formation of a number of groups. These include:

- Nundah Community Enterprises Co-op Ltd
- Nundah Community Centre Inc
- Independent Youth Housing Group Ltd
- WWILD SVP
- Redback Housing Inc
- INCH Inc

INTRODUCTION

The purpose of the *Journeys of Exclusion* research has been to explore the relationship between statutory child protection and experiences of exclusion in the lives of children and young people who have an intellectual disability. The specific focus of the project has been on the impacts on family and community relationships when children journey through and finally exit the care and protection of the state.

The research question for the project has been:

“What are the impacts on family and community relationships and connectedness for young people with an intellectual disability as a result of journeying through and, in particular, exiting the care and protection of the state?”

This report will attempt to make the lived experienced of children/young people with intellectual disabilities who have journeyed through the alternative care system real and ‘visible’ to the reader. We will demonstrate and discuss the journeys of exclusion that this group of people experience.

The majority of the 43 young people who have been the focus of this study have experienced poor life outcomes since exiting the care system. These outcomes are illustrated in the following snapshot.

Snapshot

Average age of the participant – 20.5 years
Number of males – 14
Number of females – 29
Percentage who are parents – 42%. (These young parents are mothers are aged between 17 and 24 years.)
47% have more than one child. One has three.
In total, there have been 26 children born to these 17 mothers. The eldest of these children is now 4 years.
One baby is now deceased. One of the parents is also deceased.
There have been 12 Child Protection Orders and 22 Child Protection Interventions for these children. Only one family has NOT been subject of a child protection intervention.

On average, 2 ½ years after exiting care, only one participant was still in the same accommodation. This was a private arrangement whereby they could continue to live with their foster carer. The rest of the participants have experienced several types of accommodation:

- boarding houses (40%)
- homeless shelters (30%)
- public housing, private rental, and foster carers.

Other types of “housing” include: on the streets, girlfriend’s house, prison, nursing home, and community housing.

Almost 60% have shared with another person.

Over half of the participants (59%) have experienced homelessness.

Almost one in five (17%) of these young people has been charged with a criminal offence, with 10% being charged with more than one offence. One is currently in prison. One person has been reported on several occasions for indecent sexual behaviour. The varied offences have included: theft, fraud, drug possession, assault, rape and burglary.

Of concern is the evidence that certainly 71%, and possibly 88%, of participants have been victims of crime. Only 3 of the perpetrators of these offences were convicted of the crimes. The vast majority (67%) of the crimes perpetrated were of a sexual nature, that is, sexual assault and rape. Domestic violence, theft/burglary and financial exploitation were other forms of crime committed against the participants. Overwhelmingly, these crimes were reported initially to service workers – 73%.

Contact with mental health services was reported in 60% of cases, and 44% are reported to have engaged in substance abuse. Alcohol is the most commonly abused substance (76%).

Almost all the participants (94%) are unemployed. Only two of the participants are reported to be in open employment. Only 13% obtained a Year 12 certificate and 15% a Year 10 certificate

Both research and practice experience illustrates the extensive and pervasive nature of disadvantage experienced by people with an intellectual disability (see, for example, Batshaw, 2002; Hayes, 2002; Middleton, 1996). Research and practice indicate that people with an intellectual disability are vulnerable to:

- victimisation and abuse;
- exploitation;
- isolation; and
- poverty.

These are commonly exacerbated by experiences of family breakdown, leading to:

- the absence of a caring adult figure who can exercise care and responsibility;
- few relationships beyond family, and few or no informal support networks;
- difficulty forming and judging trusting relationships;
- experiences of unstable and/or unsafe living arrangements.

The vulnerabilities that people with an intellectual disability experience result in contact with systems and services, including:

- significant contact with the child protection system, both as children and young people in need of protection and as parents;
- over-representation in the criminal justice system as perpetrators of crime and as victims of crime, and contact with the mental health system as a result of the high incidence of acquired mental illnesses.

The research also suggests that contact with these systems is a poor substitute for the protective qualities of normal family and community life (Hayes, 2002; Goodfellow & Camilleri, 2003).

Intellectual Disability (ID) Defined

The term 'intellectual disability', is often used in conjunction with, or instead of, other terms. Mental retardation is more frequently used in the United States and Canada, while in the United Kingdom the term 'learning disability' is common. In this report we refer to people with an 'intellectual disability', which is the usual Australian usage, although when reporting from United States or United Kingdom sources we will use their language.

The two classification systems used by psychiatrists when diagnosing mental retardation are the World Health Organisation's *International Classification of Disease and Related Health Problems 10th Revision* (ICD-10), and the American Association of Psychiatrist's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV).

In both these classification systems, the levels of severity are defined by standardised Intelligence Quotient (IQ) ranges that generally commence at two standard deviations below the mean of 100, meaning that an IQ below 70 indicates impaired intellectual functioning. The approximate IQ ranges for the different levels

of severity for both the DSM-IV and the ICD-10 are mild (50-70), moderate (35-49), severe (20-34) and profound (below 20). It should be noted that the DSM-IV definition uses IQ ranges as the sole determinants of levels of severity, whilst the ICD-10 classification relies on both IQ scores and the amount of support required. The ICD-10 reflects the gradual move away from the sub-classification of mental retardation/intellectual disability based solely on IQ ranges.

It is important to note, however, that the American Association of Mental Retardation (AAMR) proposes another system of classification for mental retardation/intellectual disability that is often referred to in Australia. In the 9th Edition of their manual, the commonly used 'mild, moderate, severe and profound' levels of severity were omitted, on the following grounds:

- a) *Mental retardation relies on both limitations in IQ and adaptive skills, whereas an individuals' 'level of severity' is based only on IQ;*
- b) *The accuracy of IQ scores at the extremes of measurement is regarded as less reliable than those closer to the mean;*
- c) *"Mild mental retardation," a condition that represents considerable disadvantage, is a misnomer; and*
- d) *Too much trust is put in a person's sub classification which often influences the perception of potential special education placement and types of services as well as adult opportunities for services. (AAMR 2002, p.26)*

This change in classification recognises that the term, 'mild' mental retardation, which describes a level of intellectual functioning as being 'mild' compared to others with lower IQ scores, can be misunderstood as being 'mild' compared to the general population. However, a growing body of evidence demonstrates that there is nothing 'mild' about living with an intellectual disability, and that these individuals are consistently overrepresented in many areas of social disadvantage and experience high levels of abuse and exploitation (O'Connor & Fowkes, 2000; Tymchuk, Lakin & Luckasson, 2001).

Instead of using the traditional levels of severity, the AAMR manual recommends that people use an alternative sub-classification to reflect the levels of support required by people, rather than simply their IQ score (AAMR 2002, pp.100-101). This classification is referred to as the ILEP system which lists the levels of support required as Intermittent, Limited, Extensive and Pervasive (AAMR 2002, p100). The

classification of severity using the ILEP system of supports would require the consideration of:

- a) time duration (how long a support is needed)*
- b) time frequency (how often support is needed)*
- c) settings in which the support is needed*
- d) resources required for the supports (e.g. cost, personnel)*
- e) the degree of intrusiveness on people's lives (AAMR 2002. p.101).*

With these considerations in mind, the AAMR manual outlines the ILEP system of support intensities as follows:

- Intermittent support refers to support that is required on an 'as needs basis' which is characterised by its episodic or short-term nature: for example, assistance during an acute medical crisis. This level of support can be of either high or low intensity at the time of provision (AAMR 2002. p.152).
- Limited support is characterised by consistency over time but remains time-limited (not intermittent). It will usually require fewer supportive people and will be less expensive: for example, time-limited training for employment or assistance through the transition from school to adulthood (AAMR 2002. p.152).
- Extensive supports are characterised by long-term regular involvement in at least one particular environment, for example, school or work (AAMR 2002. p.152).
- Pervasive support is characterised by constant, high intensity support across a number of environments and is often life-sustaining. Pervasive support typically involves a number of support people and is more intrusive than other supports (AAMR 2002. p.152).

The ILEP system of support intensities is based on a holistic view of mental retardation/intellectual disability, and replaces the potentially confusing and erroneous terms 'mild', 'moderate', 'severe' and 'profound'.

Characteristics of Intellectual Disability

Given the confusion and debate about a 'scientific' definition of intellectual disability, it is not surprising that there is also confusion in the ways society deals with people with an intellectual disability. Further, not all people with an intellectual disability are immediately recognisable as such. There are broad ranges of ability levels across intellectual disability, and many people are not diagnosed with an intellectual

disability until after they enter the schooling system. Some of the ways intellectual disabilities can be manifested are: poor memory; poor problem solving ability; developmental delay with slow milestones; poor understanding of consequences for actions; poor logic and a poor grasp of social rules. Communication skills are often poor and, because there is often a lack of understanding of what is being said or asked, the ability to answer or respond is greatly compromised.

Social relationships create perhaps the greatest difficulties and the greatest risks. For example, people will often go along with what others say without really understanding the meaning or implications of what is being said, and this can make them very vulnerable to exploitation. People with an intellectual disability are also more likely than their peers to give in to persuasion, and they are more likely to be selfishly and unethically used by others. Cocks (1998) describes such heightened vulnerability in these terms: *'in comparison with others, bad things are more likely to happen to them and the impact of those experiences are likely to be much greater'* (p.81)

Invisibility of Intellectual Disability

Intellectual disability is sometimes described as a hidden or invisible disability. First, as noted above, it may not always be obvious that a person has an ID, and people with ID may initially look and act like their peers. Second, in an attempt to pass as normal, people can become skilled at adapting their behaviour to mask the fact that they have an ID (Edgerton, 1967).

The majority of the general population often do not see the needs or recognise the difficulties this group of people face throughout their lives. This is no less true for the child protection system. There is, to date, no record in child protection data of the disability status of children in care. The Australian Institute of Health and Welfare (AIHW) collects data on children who are involved in child protection but, as they note, there is no data item *"that would enable the disability status of children involved to be established or estimated"* (AIHW, 2004. p.99).

Children with disabilities in care are also invisible in the research literature, particularly in Australia. A recent audit of out-of-home care research (1995-2004) in Australia did not identify any specific research about children with disabilities in care (Cashmore & Ainsworth, 2004). Some research is reported from the UK and USA and some statistics are recorded in these countries (Geenan, 2004; George & Van

Hooris, 1990). It is only from these external sources that we can project estimates of rates of children with disabilities in care in Australia.

THEORETICAL CONCEPTS

Two theoretical concepts were used to underpin this research: social inclusion/exclusion and social capital.

Social Inclusion/Exclusion

There is a multitude of definitions of social inclusion/exclusion. Most definitions concentrate on the exclusion aspect. For example, the European Foundation describes social exclusion as *“the process through which individuals or groups are wholly or partially excluded from full participation in the society in which they live”* (1995, p.4). Another definition by Barry (1998, p.1) defines social exclusion as:

multi-dimensional disadvantage that severs individuals and groups from the major social processes and opportunities in society, such as housing, citizenship, employment, and adequate living standards, and may be manifested in many forms, at various times and within various sections of the population.

Social Capital

Social Capital has, as its basic tenets, norms of social trust and reciprocity. Social capital is a resource that facilitates cooperation within or between groups (Productivity Commission, 2003).

Service providers and government officers have been encouraged to consider both concepts in order to improve services and life outcomes for people with disabilities (Bates & Davis, 2004; Chenoweth & Stelik, 2004).

Inclusion invokes basic principles of membership, friendship, relationships and supports (Chenoweth & Stelik, 2004 p.60). Social inclusion for people with disabilities, as explained by Bates and Davis (2004), means having *“fair access to activities, social roles and relationships directly alongside non-disabled citizens”* (p.196). On the exclusion end of the spectrum, Cashmore and Ainsworth (2004) make the point that the total lack of identified research on children with disabilities in out of home care *“reflects the ‘excluded’ status of these children in the area”* (p.24). Exclusion is heightened in leaving care experiences. When state care and protection orders expire for young people at age 18, they are required to transit to independent

status. Even in the general population, young people are taking much longer than before to leave the family home. Young people leaving care are, however, excluded from this prolonged and supported transition to independence.

And “they leave care in a comparatively disadvantaged position. The vast majority will have experienced the negative effects and developmental delays of the abuse during the formative years of their childhood and subsequent involvement with the legal, care and protection system. Research ... tells us that this trauma leaves a lasting negative impact on these young people, and puts them developmentally behind their peers from the start” (Raman, Inder, & Forbes, 2005 p.9).

The situation is exacerbated for young people with disabilities. Priestly and Rabiee (2003) point out that young people with disabilities often do not understand what might happen for them when they leave care. Beth, who is about to turn eighteen and leave care, says:

“Where do I go from here? ... I haven’t got a clue what it’s about or anything really, no information at all ... I’d like to know what rights I’ve got now I’m nearly eighteen ... That isn’t clear at the moment” (Priestly and Rabiee, 2003 p.881).

The much vaunted ideals of social inclusion for people with disabilities have not been realised. There is still a wide gap between the ideals of inclusion and the lived experience of exclusion.

If relationships are central to social inclusion, they are also core elements of social capital which stresses the importance of the web of connections between people and groups. This is not new, of course. Sayings such as, *“It takes a whole village to raise a child”*, reflect the age-old understanding that people need to feel they belong. Other well-established cultures value interconnectedness and belonging as essential to a good life. For instance, Native Americans value and understand the need to belong, as do Australian Indigenous peoples.

In modern psychology, Maslow claims that a sense of belonging, good relationships and feeling loved must be attained before a person can move up the ladder of the hierarchy of needs to self-actualisation (Hanley and Abell, 2002). Relationships that engender a sense of belonging make the person feel accepted, needed and loved by

others. Without this need being met, people become lonely and depressed and experience social anxieties. For people with disabilities, not feeling as though they belong is too often a constant daily experience.

Thinking of families made me sad. All I wanted was a Mum to love me and cuddle me when I cried, and a Dad to play football with to my childish imagination, fishing in the stream was a thing a normal boy would do – but I wasn't a normal boy. " Somehow I must be bad" (Robinson & Sloggett, 2003, pp. 18, 21-22).

When we use the concepts of social capital and social inclusion as a frame of reference, we are highlighting people's needs to belong and have healthy lasting relationships.

LITERATURE REVIEW

Research about children/young people with disabilities in out-of-home care is known for its paucity. As previously mentioned, Cashmore & Ainsworth (2004) in their audit of ten years of Australian research into out-of-home care did not identify any research that reported on young people with disabilities. There is considerable literature on young people in foster care, and on young people leaving care, but very little literature on young people *with disabilities* in care or leaving care.

One reason why children in care have not been subjects of research is for ethical reasons (Morrow & Richards, 1996; Mulderij, 1996), and another reason is that there are no reliable data bases that can be statistically analysed. One of the few pieces of research on youth with disabilities in care asks the question, "*Are we ignoring youth with disabilities in foster care?*" (Geenen & Powers, 2004). The answer would have to be 'yes', particularly in light of the national audit mentioned above (Cashmore & Ainsworth, 2004).

The leaving care literature highlights the poor outcomes for many young people who have been through the care system. The recurring concerns and disadvantages include: homelessness; drug/alcohol use and abuse; poor mental and physical health; poor educational outcomes; poor employment opportunities; poor social support; juvenile prostitution; crime and early parenthood (Commonwealth of Australia, 2005; Green & Jones, 1999; Horrocks, 2002; Mendes & Moslehuddin, 2003; Raman, Inder & Forbes, 2005). A recent Victorian study (Raman, Inder & Forbes, 2005) demonstrated that young people leaving care are 'ill prepared to face adult life on their own' (p.25). Young people with ID leaving care experience heightened vulnerability, because their experiences are compounded by their limited skills.

In what follows, we review the literature on the vulnerabilities of young people with intellectual disabilities in terms of their communication difficulties, their contact with the criminal justice system, their homelessness, their education outcomes, and their parenting issues.

Communication Difficulties

Poor communication skills impact on daily self-help skills for people with ID, for example, when having to deal with Centrelink, banks and other officials, even going to the doctor. It is difficult for people with ID to understand the complexities of such systems, but many will try hard to appear to manage. For many people with ID, it is important to be accepted as, or “pass” as, normal. An early study by Edgerton (1967) describes how people with an intellectual disability are acutely aware of the stigma of disability and, because interpersonal competence is the most challenging arena, it is the area where “passing” is seen in its classic form. In the attempt to “pass”, people will “*often dissemble, lie or fake in most ingenious fashion*”, and it is therefore the area where there “*is the constant danger of failure, disclosure, and shame*” (p.162).

A particular problem arises for people with intellectual disabilities in their literal translation of what is said. A story from a book by Schwier (1990) highlights this. A young man had noticed a young woman he found appealing. They both had an ID. Because he wanted to get to know her, he decided to ask her out. This is how he recounts the story: “*So I asked her out for a cuppa coffee. She said no. So I asked her if she wanted a cup of tea. She said, ‘Well, tea, sure.’*” (p.26). They went on to become happily married. The point of the story is that, if the young man had taken the first answer of “no” to coffee, the romance could well not have blossomed. People with ID often do not understand the inferences or the nuances in conversations. In the above story the young man had to get the exact meaning of what she liked to drink, so he logically moved on to ask her out for a different type of drink, and got the desired response. Many non-disabled people would not have reworded the question to get the right response. When interviewing people with ID, non-disabled people can misunderstand responses because they are using incorrect questioning techniques and not taking account of literal responses. When people with ID come in contact with the criminal justice system, their poor communication skills severely disadvantage them, and the outcomes are often unjust.

Contact with the Criminal Justice System

It is well documented that people with ID are over represented in the criminal justice system (Byrnes, 1999; Cockram et al, 2005; Hayes, 1997; Hayes, 2002). Byrnes (1999), for example, reported that one third of people appearing in NSW courts were people with ID, and Lewis and Hayes (1998) observed that people with ID are “*more*

prevalent in prison than in the community” (p.19). Similarly, the leaving care literature points out that young people who have journeyed through the child protection system have a high incidence of involvement with the criminal justice system (Priestley & Rabiee, 2003; Raman et al, 2005; Reilly, 2003.). The combination of these vulnerabilities – ID and the experience of child protection – means that such young people are at high risk of coming into contact with the criminal justice system. There appears, however, to be no literature that reports any investigation of this matter.

Homelessness

Homelessness is a frequent outcome for vulnerable young people with ID who lack appropriate supports, and who perhaps also have a mental illness or are leaving care (Drew, 1998; O’Connor & Coleman, 1995; 1996). A study conducted in NSW in 1995 found that young people with intellectual disability are at greater risk of chronic homelessness than their peers and are overrepresented in the homeless population (NSW Council for Intellectual Disability & Opposition Youth Crisis Centre, 1995, 1996).

Education Outcomes

Providing appropriate education for children and young people in care is a well recognized problem. A US research report by George & Van Voorhis (1990) claims that, *“More than six times as many foster children receive special education services”* as those in the non-foster population. Another US report claims that approximately 40% of adolescents in foster care have disabilities and require special education (Geenen, 2004). *“Foster children in special education are older, on average, than the general special-education population”* (George & Van Voorhis, 1990). The study by Geenen (2004) claims that, of the 20,000 youth who leave foster care each year in the US, only 54% have graduated from high school. It would be sage to assume that, for the 40% with disabilities, the rate of graduation would be much lower than 54% and that the situation would be similar in Australia.

Poor education leads to few employment opportunities and high unemployment which, in turn, leads to low income and poverty. Poverty leads to crime and homelessness. It all seems like a downward spiral, and it often is, and people with ID commonly lack the skills to find a way out. If they are, in addition, exiting care, they are likely to have few social supports and no social capital. Emerson (2004) writes:

“The association between poverty and intellectual disability suggests the importance of targeted interventions to increase both the personal capital and the personal social capital available to children with intellectual disabilities and their families” (p.331).

Parenting Issues

Yet another issue of concern for young people with an ID leaving care is that of fertility and parenting. In Australia, there are, *“40,000 children under five who live with a parent with a learning disability”* (Healthy Start, 2005).

When women with ID become mothers, people commonly raise concerns. It is often presumed that the young woman will not be able to provide adequate parenting, but research by McConnell et al (2003) confirms earlier research by Feldman et al (1985) that there are no significant variations from the norm in the quality of the home environment provided by parents with ID. In the McConnell et al (2003) research, however, children of parents with an ID, who themselves did not have an obvious disability, were found to have delayed language skills. There is a real dilemma in these situations where the needs of the parent with a disability and the well-being and safety of the child are seen to be competing. For child protection authorities, as Fitzgerald (2006) points out, the priority must be to make sure the child is safe. However, the parent with an ID also has needs and abilities, and these must not be dismissed out of hand. As Fitzgerald (2006) points out, *“an advocate...may be an essential support for some parents”* (p.12).

There can be tragic outcomes when these issues are not addressed appropriately or adequately. The case of Baby Kate, reported in the Crime and Misconduct Commission (CMC) report, *“Protecting Children: An Inquiry into the Abuse of Children in Foster Care”*, documents the tragic death of the baby of a young mother who had been in care herself and who had an ID. The report states that the mother's *“social and intellectual functioning is at a very low level and she is extremely vulnerable ... [she] has difficulty managing her own hygiene, health and daily care”* (Crime & Misconduct Commission, 2004, P.85).

The literature shows that young people with an ID, whose lived experience has included a journey through the child protection system, face such great disadvantages that they have little chance of succeeding in life. Their experiences leave them in a state of heightened vulnerability where, as Cocks (1998) writes, *“in*

comparison with others, bad things are more likely to happen to them and the impact of those experiences are likely to be much greater” (p.81). The double disadvantage of having a disability and a childhood spent in the care and protection of the state may also increase the likelihood of mental health problems. While the literature reports experiences of a life in care or the experience of disability, and the effects of these disadvantages on life outcomes, the literature does not report on the double disadvantage and its effect on life outcomes.

RESEARCH PARTICIPANTS AND METHODS

Participants

There were four groups of people who provided data for this research:

- young people with an intellectual disability who had exited child safety intervention at age 18;
- former foster carers of these young people (all of the former foster carers had retained a connection with the young person post foster care);
- workers in services who came into contact with these young people, usually though not always post exiting care;
- managers/co-ordinators of services that were used by these young people post exiting care.

The primary participants were the young people at the centre of the research. For these young people to be participants in and contribute to the “Journeys of Exclusion” research project, they had to meet the following criteria. They had to have

- an intellectual disability;
- some experience of abuse and/or neglect or family conflict; and
- some history of child protection/foster care.

While many participants had had negative life experiences, resulting in marginalisation and disadvantage, researchers were also interested to hear the positive aspects of their life experiences. Participants were not excluded from the research on the basis that their stories were predominantly positive rather than negative. However, it was extremely difficult to find truly positive stories in the life experiences of these participants.

Data Collection Methods

There were four methods of data collection.

- The first method was a questionnaire designed to be filled out by a person who knew someone who fitted the research participant criteria. The people who filled out these questionnaires are referred to as “workers”, and they were contacted because they could source those who had knowledge of and/or relationships with the young people. Once young people had been identified through service contacts, past foster carers were also contacted to help with

questionnaires, as it was considered they could often provide a rich source of data due to their long-term and in-depth relationship with participants. Forty-three questionnaires were returned from a total of 75.

- The second method was personal interviews with eight of the young people who had been identified through the questionnaires. The purpose of conducting individual interviews was to gain qualitative data that might not have been elicited through the questionnaires. Because the researchers sought to capture in-depth, quality information about the person's family and community life, they asked interviewees about the following areas: relationships; being in care; places lived; school experiences; social activities/time usage; and health issues. To assist researchers gain an understanding of their relationships with other people, a tool called Relationship Circles was used. The circle drawings enabled participants to map the significant people in their lives in terms of their proximity to themselves. The figure in the centre of the circle represented the person being interviewed, and the other circles represented 'closeness' or 'significance'. For example, a person could choose to place an aunt with whom they were particularly close in the nearest circle to themselves. The friendly man from the fruit shop might be placed in the far circle because he was only an acquaintance. The exercise allowed both the participant and the interviewers to gain a sense of the significant relationships in the interviewee's life, particularly in relation to family. In this report, the participants who were interviewed will be known as Trevor, Nathan, Matthew, Liam, Nick, Chelsea, Mary and Naomi.
- The third method was individual interviews with managers/co-ordinators who had had significant experience in service provision with people with intellectual disabilities. These interviewed tapped into the workers' own intuitions, learnings and practice expertise (but not necessarily the views of their organisations). Collectively, the group of five managers interviewed had had over 70 years experience in the field. The managers were selected to cover areas of service related to homelessness, parenting, accommodation support, out-of-home care and lifestyle support. They will be referred to as Manager 1, Manager 2 etc.
- The fourth data collection method was semi-structured interviews with past foster carers of young people with an ID. The five foster families who were interviewed had cared long-term for a young person with an ID and, as well, they had knowledge of the young people's experiences of exiting the care and protection of the state. The foster carers will be referred to as FC1, FC2 etc.

The main challenge in the data collection phase was finding workers who had known participants for a reasonable length of time. Because of their constantly changing life circumstances, participants do not know many people for lengthy periods. As a consequence, there are gaps in the data obtained from the questionnaires (and so gaps in what can be reported).

⇒ Note: When percentages are stated, they have been calculated on the numbers of responses to a question, and exclude missing data. For example, there were 43 returned questionnaires but not all participants filled in every question. If there were 5 missing responses, the percentages were calculated on the basis of 38 responses. All ethical considerations were taken into account, with particular attention to issues of confidentiality, dignity and respect. Copies of the tools for data collection (questionnaires etc) are available on request.

FINDINGS AND DISCUSSION

Several themes emerged during the research project. The themes in order of discussion here are: parenting; accommodation and homelessness; criminal justice issues; health and substance abuse; education; employment; relationships; and the related issues of vulnerability and the need for ongoing support. These are not discussed in order of significance because all these issues affect the lives of people with intellectual disabilities.

(a) Parenting

Almost half the young people interviewed are parenting a child, and all these people are female. (Of total female participants, 61% are parents.) The average age of the mothers is 20.8 years, with a range of 17-24 years, and almost half of them (47%) have more than one child. One mother has three children. There have been 26 children born to the mothers. One child is now deceased, one of the parents is also deceased, and 42% of the infants are in care. One child lives in a private foster arrangement. Only one family has not had any form of protective intervention: that is, 25 out of the 26 children have had some form of child protection intervention in their lives. The oldest of these 25 children is three. There have been 12 Child Protection Orders taken.

17 mothers, 26 children, one 3 sibling group, eight 2 sibling groups, 7 only children. 1 child deceased. 1 mother deceased. Mothers' average age 20.8 years. A child protection intervention rate of 96%.

Lisa's Story

The Crime and Misconduct Commission reported that Lisa was disinterested in *"obtaining any pre-natal care for her unborn baby"* and that this suggested *"a serious lack of insight and understanding of the needs of both herself and the baby"* (CMC, 2004, p.83). Lisa is not a stand alone case. Manager 4 had this to say about mothers like Lisa: *"Birth for this group of mothers is actually quite dangerous. In the days when you had a GP that you had a relationship with and you liked that doctor, it would have been better for these Mums. ... They are tending to present at 34-35 weeks. Women are presenting in labour and the hospital has not seen them before."*

Manager 4 reported that over half of the mothers they support in their service have been in some form of alternative care, living away from their families of origin during their childhood.

Naomi's Story

Naomi is a young mother of three, and FC2 are her foster parents. Naomi's youngest child is living with her, her first child is in care, and her second child lives with the father. Naomi, with her new partner and the father of her youngest child, is trying very hard to get her oldest child back. FC2, who have been foster parents for about 30 years and are now foster grandparents, deliberately chose not to foster Naomi's children because "*we wanted to remain friends with Naomi.*" They knew that if they had fostered Naomi's child, she would have turned against them and they would not have been able to help her. Now they are still involved in Naomi's life and are able to provide support to her and her child/ren. Naomi has reached a point in her life (after some turbulent and rebellious years) where she now turns to her foster parents for advice and practical help. That outcome is what the foster parents had hoped for.

Ellie's Story

FC1 was Ellie's foster mother. FC1 cares for Ellie's first child through a private arrangement. Ellie has had two children, and she is the primary carer of the youngest child. FC1 is still able to have "*that kind of Mum thing going*". By this, she means she can still go around to Ellie's house and give her some friendly advice and, at times, some blunt direction. Ellie had her first child less than a year after exiting out of care at the age of 18, and her second child eighteen months later. FC1 believes that, if the second child were removed, there would be a third child and, if that one were removed, there would be a fourth, and so on.

Minnie's Story

FC3 was the foster mum to Minnie who has a nine month old baby and is pregnant again. There will be 16 months between the two babies. Minnie officially left the care of FC3 when she was 16, and moved to another foster family. That only lasted a very short time, and then she moved in with her natural mother. This, too, only lasted a matter of weeks. She was exploited sexually and financially in both places. She then fended for herself on the streets, at times resorting to sexual favours in return for a place to sleep. She had lived with FC3 since she was three, and FC3 is the person to whom Minnie turns for help and advice. She has been caring for the

first baby quite well, but FC3 is worried about how she will manage with two babies. Currently, Minnie is living in a country town with no service support.

The foster families of these young mothers give important and ongoing support to their former children. Their foster roles have not ended when their foster children turned 18. As FC2 said, “*Care never finishes. Even to your own children and grandchildren.*” The foster carers are now involved in caring for the children of their foster children. Since these stories were collected, Naomi has been successful in having her first child returned to her care. Naomi is receiving no extra support on the return of this child who has significant disabilities.

(b) Accommodation and Homelessness

What constitutes a home? Shelter, belonging, safety, security and warmth. It could well be argued that the majority of the young people in this research do not have a home. They may have a place to shelter from the elements, they may even have an address to receive mail, but their constantly changing accommodation arrangements, along with no long-lasting relationship in their life to share them with, would make it difficult for a person living like this to call where they live at home. During their journey into and through care and in their post care experiences, they have experienced a high level of mobility. Only 14% of the 43 participants had experienced just one placement while in care. All others had had multiple placements.

While in care, 26% of participants had experienced more than five placements. Some had 22, some over 40 and some over 50. 46% had two or more placements, while only 14% experienced one placement.

Post care accommodation. 14% of participants continued living with their foster carer. 41% moved to supported accommodation. On average, 2.½ years after exiting care, only one participant was still in the same accommodation (with a foster carer through a private arrangement). All other participants have experienced several types of accommodation including: boarding houses (40%), homeless shelters (30%), public housing, private rental, and foster carers. Other types of “housing” include: on the streets, girlfriend’s house, prison, nursing home and community housing. At the time of the questionnaire, 59% were sharing with another person.

Over half of the participants (54-59%) have experienced homelessness.

The transient nature of much of the accommodation participants have experienced is not always understood as homelessness. Many participants have lived in many places since leaving care. Matthew's list, for example, includes Woolloongabba, Ascot, Doomben, Slacks Creek, Clayfield, Woolloowin, Calamvale, and Annerley, both in units and in houses. Matthew says Annerley was best because it was close to the train and he *"had friends in the street"*. Nick's list is as long as his 22 foster care placements. Mostly, he has been living in somebody else's house, such as at a friend's house or brother's house or girlfriend's mother's house. People take him in, and later, as Nick said, he gets *"kicked out"*. Where he sleeps may be on a couch or some spare spot in a house. One time, after being in a homeless shelter, he found a place to live with the help of a service. He liked it there and wanted to stay, but he had to get out because he was being threatened by a man he had met at the shelter. Nick said: *"He had nowhere to live, so I took him in. I wanted him to leave but he wouldn't. I went to work one day and, when I came back, he had taken all my stuff."* Nick then lived with his Mum for a little while, but eventually she, in Nick's words, *"kicked me out"*.

Another participant, Naomi, described one of her experiences of homelessness: *"I was homeless for a while. I was with this guy Sam. And then I split away from him, stayed in some flats at Kallangur, and then somehow Sam and I found each other [again]. He moved into one of the flats. Then we were on the streets for 3 months, getting chased by the Police, seeing the Salvos, trying to find a comfy place to stay ... I got sick"*.

One foster family recalled a former foster son's (Dean's) housing experience, as follows: *"There were this couple who come into and took over his flat, sort of thing. They took over his credit card. They got his PIN number and they would not give him anything. Fortunately, we have got a son-in-law who is built like a tank. Dean managed to ring him one afternoon and he got one of his mates (who is even bigger). They are big bikie looking fellows and they went in. They said the fellow that was there was a great big fellow. He was over six feet, but they turfed them out, and said, "Don't you ever come back here". My son, who is a carpenter, went and fitted proper*

locks and that ... But he slips into that sort of situation so easily and frequently. And part of it is loneliness. He is wanting friends. He has been bashed up...

Not all participants have experienced homelessness. One participant, Trevor, was able to move out of home successfully with the help of a service provider. Another participant, Mary, has also been able to live in her own place since she was 18. She received a good funding package under institutional reform funding, thanks to the service that has supported her since she was twelve.

The service managers had a depth of knowledge about accommodation issues. Manager 4 talked about the isolation families experience when they have to move, even when it is not far away. When they move, they lose their established networks and get "lost". There are no familiar faces in the streets. In one case, it took a person six months before they started to settle in, after a move of approximately 3-4 kilometres from one suburb to another. Manager 4 pointed out that, "Developing an understanding of bus routes, of traffic flow and many other things that are just taken for granted prove really difficult for people with ID".

Manager 3 identified some of the issues in exiting from care. One young woman is about to turn 18. Her service support has had supports in place that have worked successfully for a number of years and have improved her quality of life. The manager explained that her living arrangements will have to change when she transits from DCS funding to DSQ funding. The manager is concerned that, when case management responsibility is handed over to DSQ, all that success is at risk of being lost. Prior to coming into the service, the young woman often behaved in a violent manner. When her living arrangements and support program have to change, it is likely that her violent behaviour will return.

Several managers raised similar issues. Some young people with an intellectual disability, though by no means all, will receive a Placement Support Package whilst in care. These packages, often of the order of hundreds of thousands of dollars, are to provide for the particular needs of the child with a disability whilst in the care of Child Safety. When the young person with a disability who is receiving a PASP package exits Child Safety, they will usually be transited on to a DSQ Disability Support package. This funding package will usually be as low as one third or a quarter of what they received while in care. The needs of these young people remain the same, of course, and may even become more complex with adulthood. There is

an apparent lack of logic in a system that determines your need for support at hundreds of thousands of dollars one day and a quarter of that amount the next, only by virtue of the fact that you have become one day older.

However, for those who have had PASP funding while a child in care, there is some (however inadequate) ongoing funding. For the majority of young people with ID in care, there has been no funding package, and so they exit state care without any provision for ongoing support. While these young people with ID are in care, it is the foster carers who do the hard work of trying to ensure their special needs are met. A number of the foster family interviewees spoke of their fears for the future vulnerability of the young person leaving their care. They were fears that they felt Child Safety departmental officers were oblivious to.

The above stories of Matthew, Naomi, Nick and Dean show how vulnerable they are and how they lack the skills to settle into permanent accommodation. The loneliness they experience and their need for relationships lead them to connect with people who take advantage and exploit them. The Victorian study, "Investing for Success" report, found that, in 32% of cases, the transition plans for the care leavers direct them to use programs for the homeless (Raman et al, 2005). The question has to be asked, "How can young people with ID and no support networks be expected to find adequate housing?"

(c) Criminal Justice

- Criminal charges. 17% of the participants have been charged with a criminal offence, and 10% with more than one offence. One person not charged has been reported on several occasions for indecent sexual behaviour. The offences committed vary significantly and include theft, fraud, drug possession, assault, rape and burglary.

17% charged with crime. 10% charged with multiple crimes. One reported several times. Offences include theft, fraud, drug offences, assault, rape and burglary.

- A concerning 71% and possibly 88% of participants were reported as having been victims of crime. Only 3 of the perpetrators were convicted of the crimes. 67% of the crimes were of a sexual nature, that is, sexual assault and rape. Domestic violence, theft/burglary and financial exploitation were other forms of

crime committed against the participants. In 73% of cases, crimes were reported initially to service workers. That participants would report the crimes to workers illustrates how few people there are in the lives of these young people to whom they can turn in time of need.

71% (minimum) were victims of crime, but only 3 perpetrators were convicted. 67% of crimes were either sexual assault or rape. Other crimes included domestic violence, theft, burglary, financial exploitation.

(d) Health and Substance Abuse

60% have accessed mental health services. 44% are reported to have substance abuse issues.

- 60% are reported to have had some contact with mental health services. There are probably a few more than this because, while some have not been given a diagnosis, they are on medication and seeing a psychiatrist. In 10% of cases, their mental health status was uncertain.
- 44% of young people are reported to have engaged in substance abuse, with alcohol being the main substance (76%). Other substances include marijuana, amphetamines, prescription drugs, paint and chroming. Only 3 young people have accessed drug rehabilitation.

(e) Education

12% have gained a Junior Certificate; 12% have gained a Senior Certificate. 2 of the participants were still at school. The remainder of the participants were reported as having gone to special school, or the worker had no knowledge of educational outcomes.

Mostly negative experience, 25%; mostly positive experience, 4.6%; neutral experience, 16%. Workers did not have knowledge of the school experience for the remainder of the participants.

Trevor:- *“The message is to stop bullying in schools.”*

Nathan:- *“School sucked!...I call myself a bit of a bully but when at normal school I was eaten alive.”*

Matthew:- *“A teacher grabbed my hair and smashed my face on the table [but there were] some good teachers.”*

Chelsea:- *“School’s not really that good ... I didn’t have many friends.”*

Liam:- *“Relief teacher gave me a hard time.”*

Naomi:- *“It was hell ... I would advise my kids never to go because you get teased and picked on at all schools. The headmaster didn’t like me and I didn’t like him.”*

Mary said, *“It [school] was alright, got to learn new things, make new friends.”*

Matthew had this to say:- *“I really liked school as it helped with education and teachers were caring and understanding.”*

The majority of the comments about school were not related to educational outcomes, but about what it felt like being at school and how people were treated. (There were only two interviewees who had something good to say about learning.) The data gathered from the interviews showed that, throughout their school life, the quality of the education they experienced was measured by how many friends they had, and by how much they were picked on, bullied or teased.

(f) Employment

Of the forty-three participants, only 25% were currently employed. 5% were in open employment, 16% in supported employment. One person was employed in prison, one sells Avon with the help of her mother, and another person’s employment wasn’t specified. The only participant who reported never being unemployed is still in school. 40% have been unemployed for more than four years; 18% have been unemployed for between two and four years. Of all participants, 94% have been unemployed at some time. One is still at school, and another stays home and cares for her child.

(g) Relationships

In the course of the interviews with participants, as well as with managers and foster carers, it became clear that relationships (or the lack of relationships) impact on many areas of the lives of the participants. The following stories illustrate some of the relationship issues that these young people face.

Nicks Story

Nick was placed in care and protection when he was 6 years old, and subsequently had 33 placements in 12 years. Nick put his father at the centre of the relationship circle. He had seen his father the day before the interview, had *“sorted some things out”*, and was able *“to get my father’s side of the story”*. Prior to seeing his father the day before, the only times he had spent with him had been once the previous year, and once three years before that. He had thought his stepfather, who is now deceased, was his father. After one visit with his father and two brothers, he felt he was very close to him. His girlfriend was the only one closer. He put his birth mother outside the outer circle because of recent events. (His mother had been granted a 12 month Domestic Violence Order against him in the previous week.) This is how he talked about his mother:

“Me whole life Mum and me haven’t got along. She neglected me. Someone signed me over to care. I think it was Mum. Dad wasn’t there. I wish we could get along. Twelve months isn’t long. Maybe she will change her mind and talk to me. There was no need for a DVO. I wanted to talk to her, not say anything bad to her, but I couldn’t ‘cause I was on a temporary order. She’s my mother. They took her side of the story, not mine.”

Of Nick’s 22 placements, he thought two were good. One lasted three years, until he was a *“naughty boy”*: he *“lit up the backyard”*. He was removed from that family and the school he had enjoyed for three years (Years 5, 6 & 7 and the beginning of Year 8). When he thinks back to that time, he says he would like to see those school friends again. After being *“kicked around”* a few places and a few schools, he *“got a call”* to go to BoysTown. He loved it there. They *“sorted me out...I did not want to leave”*. Recently, when hanging out with a friend who had a car, they went for a drive down to BoysTown to see where he had lived and speculate where all those brothers and other teachers were now. He would like to see them. Nick said. *“BoysTown changed my life. I didn’t want to leave there, but had to because they only went to Year 10.”*

Chelsea’s Story

Chelsea stated several times through the interview, *“I’ve got Asperger’s. I don’t need friends. I am a recluse”*. She has withdrawn into the world of cyberspace and is effectively living in a virtual reality. Her relationships are formed through the internet, at a safe distance, and mostly in the USA. Placed in the centre relationships circle with her is Joe, from the USA, whom she knows only on the internet, but whom she

sees as her fiancé. In the next circle, she put her former foster mother, who lives not far from her and whom she sees occasionally, and she put another person in the second circle, a friend from South Carolina via the internet. Two service workers were in the outer circle, and were described as “cool”. Knowing her diagnosis and a bit about it has helped her to shut people out of her life. What Chelsea does with her time is, “internet – sleep – food”. She rarely leaves her house. She leaves to get food, go to the computer store and occasionally visit her former foster carer. Her bills are paid through an automatic bill-paying service, and her life is a corner of her little flat in front of her ‘lifeline’ computer. She lives her life through the computer. She has relationships with many people on the internet, enjoys role plays and sets up sites and forums. The only clear floor space in the flat is at the computer where there is a folded up mattress that she puts down when she sleeps. There is a pathway through knee-deep debris from the door to her corner of the world.

Trevor’s Story

Trevor’s story highlights that, for some people, almost all their relationships are with paid workers. In the interview, Trevor placed all service support workers in the centre of the relationships circle with him. This was because he felt these were the people in his life who were the closest to him. The following are Trevor’s comments about the service providers (SP1, SP2, etc):

“Helps Trevor to achieve things.” SP1 understands Trevor and knows him well.

“SP2 helps people to stand up for yourselfsavings group helps with saving money.....allows Trevor to meet new people.”

SP3 and SP4 allow Trevor to show initiative, make decisions, respond to issues that arise, be involved in bigger issues, and to feel respected, important, privileged and to face lots of challenges. Trevor said that SP1 was rated as very important because she made possible the first step for Trevor to move out to live independently and to prove that he could do things. Trevor says he *“fills time by involvement with SP1.”*

Liam’s Story

When Liam talked about being in care, he said he badly wanted, like Nick, to have had a relationship with his birth family. He said, *“I really wanted to go back home. Used to see my family every now and then. Don’t [the Department] really want to help families get back together again?”* He also missed his first foster family. In his words, *“I should have stayed with the first place. [We] did lots of things, activities and jobs. After this, [I] had lots of places [that were] not so good. Not so affectionate and [I] couldn’t call them Mum and Dad.”*

Mary's Story

Mary is happy at the moment because she has a partner living with her and she has a close caring relationship with him. In general, she is happy because she doesn't keep negative people in her life. She has had many setbacks in life but, in her words, *"I am not Tigger, but I do bounce back"*. She has amazing resilience. Mary has had a substitute family relationship since she was about 4, and they have been an anchor in her life. All the people that she feels close to she has met through service provision. She met her current partner at an organized social activity for young people with disabilities. Services have provided her with long lasting friendships and supports.

These young people's stories show that these young men and women are constantly on the search for a sense of belonging, and that they yearn for friends and crave affection. They search for a sense of belonging, and that they yearn for friends and crave affection. They search for an answer to *"Whose am I?"* Contrary to the statement *"I've got Asperger's. I don't need friends"* and the variety of ways they use to obtain friends, including the internet, newspaper ads and phone services.

The quote for the week beginning 16th July 2006 from the Oxford Dictionary website, www.askoxford.com was:

Friendship is one of the most tangible things in a world which offers fewer and fewer supports.

This quote may help readers appreciate how these young people are missing out on both counts: friendship and supports. The participating managers in this project all recognise that these young people need supportive relationships. They have to use funding in creative ways to incorporate relationship building into their service provision, as funding does not cater for this basic need. They, along with the foster carers, are all concerned that on exit from care the young people can, in their search for belonging and friendship, so easily end up in the clutches of a predator.

(h) Related Issues

Two clear issues that emerged in this research were the vulnerability of the young people and the lack of adequate supports once they leave care.

The questionnaire included a section where respondents could report on other areas not captured in the survey. Several stories highlighted the vulnerability of these young people, of which the following is an example.

Carla's Story

Carla, a young person with ID, incurred a phone bill of nearly \$2200.00 in just 10 days. The calls were to sex lines, at a rate of \$60 an hour. One night alone, the bill was \$700.00. The telecommunications company restricted the phone calls after 10 days but wouldn't allow the phone to remain connected until the bill was paid off (out of her disability pension). The lack of a phone cut Carla off from her regular friends and service providers. She yearns for normal friendships but has difficulty keeping friends. The people on the sex lines will talk for as long as she pays. Carla does not understand the value of money, so the information about costs at the beginning of the call is lost on her.

When Carla meets a new friend and gets their phone number, she phones them incessantly – sometimes four times a minute – and hangs up when the person says hello. Her normal monthly phone bill for local calls increases by 700% when there is a “new friend” to contact. The new friends don't last long. One person even turned up at her door at 10.00pm in an aggravated state to “teach her a lesson” about the calls.

Aggravated new friends are not the only threats for a person like Carla who uses the phone to gain friendships. By responding to an ad in a local newspaper for “men wanting to meet women”, Carla was aggressively raped. The rapist was not apprehended or charged. So strong is the need for relationships that young people like Carla learn ways to get around phone disconnections. For example, a prepaid mobile phone can keep her going for a while, and topping up a prepaid mobile is cheaper than paying off a \$2000.00 phone debt. Even so, the phone and the accompanying debts do not meet the emotional need for ongoing relationships.

The young people in this project are clearly not looking to the future and making plans. Their life is about the here and now and about making connections or relationships. Some may be able to achieve that, with a lot of service help and with the support of some very committed former foster carers. Most of the participants are still searching and are very vulnerable.

After-Care Support

A minority of the young people with ID in this study received significant ongoing support from Department of Disability or other disability agencies once they left care. Those who received ongoing support had already been receiving a Placement and Support Package whilst in care, or had been lucky enough to receive an individual package through the competitive M.A.P.S. or Individual Support package process.

Most received no ongoing support as, for example, the mother of Baby Kate described by the C.M.C. “as socially and intellectually functioning at a very low level and ... extremely vulnerable. (She has difficulty managing her own hygiene, health and daily care.)” (CMC, 2004 p.85)

Paradoxically, those who might have had the most stable care experiences and might be seen as requiring the least after-care support, may also be amongst the most vulnerable: their ‘quiescence’ in care can become ‘quiescence’ and passivity in the face of exploitation once they leave care.

It is to be hoped that the new Child Safety teams within D.S.Q. will work effectively with the Department of Child Safety to recognise the vulnerability of young people with an ID leaving care. However, even with the recognition of their potential vulnerability, the question remains of how these young people are to be supported post care. It is the contention of the researchers that existing resources and systems will not suffice, and that there will need to be new resources for the long term support of this group of young people.

CONCLUSIONS

The outcomes of this research confirm that young people with an ID leaving care are within a short time of leaving care at risk of a number of negative social outcomes.

These outcomes include:

- homelessness;
- exploitation and abuse, particularly sexual exploitation;
- unemployment;
- early pregnancy and contact with child protection;
- poor mental health;
- addictions; and
- financial debt.

Contributing factors include:

- the negative effects of the abuse or neglect that they experienced as children;
- the lack of supportive adult figures once the young people leave care;
- lack of positive peer figures and relationships;
- tendency to become involved with exploitative or abusive others (who may include members of family of origin);
- their intellectual disability, which is often displayed in:
 - poor understanding and use of money;
 - poor personal care;
 - gullibility, suggestibility and ability to be coerced (one of the defining characteristics of people with an intellectual disability);
- a willingness to put up with, take as normal, accept or not understand when they are being exploited (again, another defining characteristic of intellectual disability);
- their youth (which increases their sexual attractiveness);
- their income (Disability Support Pension, which increases their economic attractiveness);
- their lack of knowledge of sexuality and birth control.

The key recommendations of the report flow from these conclusions.

RECOMMENDATIONS

Recommendation 1

That the Department of Child Safety establish a disability unit within Child Safety to provide leadership and expertise within the Department on the needs of children with a disability who are taken into care and also the children of parents with a disability who are taken into care. This unit would develop strategies to advance the knowledge and skills of departmental officers across disability practice issues. The unit could also keep statistics on the numbers of young people with disabilities in care.

Rationale: There is an over-representation of children from families with an intellectual disability in care, and of children with an intellectual disability in care, and there is general lack of expertise in the Department in relation to working with people with an intellectual disability. Middleton (1999) explains why expertise in disability issues is crucial for positive outcomes.

“Working with disabled children needs an understanding of health, welfare, education, development, family functioning, law and disability rights as well as skills in counselling, listening, advocacy and an understanding of anti-discriminatory practice. Whatever their particular background, effective workers will need competence in a wide range of areas that are unlikely to be provided as a coherent body of knowledge on any particular training course.” (p.86)

Anecdotally, we hear many child protection workers say they do not have adequate knowledge or skills to work with clients with disabilities.

Recommendation 2

That the Department of Child Safety review their policies and procedures for young people with an intellectual disability exiting care in an attempt to decrease their vulnerability. For the purpose of identification, the reviewed policies should apply to young people who are in receipt of Disability Support Pension, who have attended special school or special education units or special education classes in mainstream

schools, or who are identified as potentially vulnerable by foster carers and departmental officers due to poor literacy and numeracy skills and impaired decision making or social interaction capacity.

The review should cover:

- policies and procedures in relation to re-unification with family of origin where the circumstances of the family of origin still pose a risk to a vulnerable young person;
- the possibility that young people with an intellectual disability exiting care be referred automatically to the Guardianship and Administration Tribunal for consideration of need of an administrator and the need for Public Trustee management of income;
- early liaison (at age 15) with post-care services adept at supporting this group;
- consideration of supporting the young person with an intellectual disability to remain with foster parents.

Rationale: As this study has shown, young people with an intellectual disability leaving care are highly vulnerable. This is partly due to the fact that they are attractive targets to those who would intentionally or unintentionally exploit them. While many young people may want to reconnect with their family of origin, in many cases this has had disastrous outcomes, as the natural parent's capacity to provide protection and support has not improved. Negative outcomes result from the young person's attempts to engage fully with an 'adult' life when they do not have the capacity to do this without ongoing support.

Recommendation 3

That the Department of Child Safety and Disability Services Queensland explore how to establish and implement ongoing supports for young people with an intellectual disability leaving care. One option could be a personalised funding plan, similar to "post school options", with a minimum of \$10,000 per year for an initial period of three years for each person with an intellectual disability leaving care. The payment could be to an existing foster family to support continuation of that arrangement, to a local community service, or to a newly established service with demonstrated capacity to support this group of young people. The focus of the service work should be to strengthen the young person's existing positive relationships and build new informal support relationships.

Rationale: There is a discrepancy between the developmental delay these young people experience and the legislative and policy concept of adulthood at the age of 18. The capacity of these young people to function at an adult level at 18 years is even less than that of young people in the general population who, increasingly, stay with their families much longer than in the past. This recommendation seeks to provide specific funding so that young people with ID are supported to 'anchor' themselves to at least one safe person, service or place. While the actual numbers of young people with ID exiting care are not known, estimates would suggest that this is likely to be between 40 and 50 per year in Queensland.

Recommendation 4

That the Department of Child Safety and Disability Services Queensland jointly review the transition funding arrangements for children with disabilities leaving care. All existing and any new funding policies and programs, as well as the processes by which to apply, need to be broadly circulated to service providers and carers.

Rationale: During the course of the research a number of cases came to light where, on exit from care, a young person who was previously receiving a Placement and Support Package from Department of Child Safety would, within one day of their 18th birthday, receive a substantially lesser amount as they transferred to a Disability Services Queensland package. Available support funds were commonly cut to one third or one quarter of the original amounts. Yet their need for support did not, of course, change between 17 years and 364 days and 18 years.

Recommendation 5

That Disability Services Queensland fund a specialist agency to work with young people with an intellectual disability exiting care. This agency could collaborate with Child Safety on exit issues, identify and recruit services and provide the necessary supports to the young person, continuing foster parents and other services. The agency would have a specialist case management role, with access to the personalised funding outlined above (in Recommendation 3).

Rationale: At present there is no specific support for this vulnerable group. As their vulnerability becomes more apparent, they come to the attention of other agencies, for example, as the parents themselves of children who are under investigation by Child Safety, as homeless young people living in shelters and on the streets at high

risk, as patients in mental health facilities and in the criminal system as both perpetrators and victims of crime.

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