CARING FOR A CHILD WITH AN INTELLECTUAL DISABILITY AND CHALLENGING BEHAVIOURS

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EXECUTIVE SUMMARY

More than 100,000 children have an intellectual disability in Australia. Some young people with a profound or severe intellectual disability also have challenging behaviours – a mix which can have a significant impact on the whole family.

This research report documents the experiences of 15 such families through a series of in-depth interviews and supported by an extensive literature review. The participants had been part of a residential educational model provided by the Kingsdene School and were keen to outline their experiences of caring for a child with a significant intellectual disability combined with challenging behaviours.

The research shows that intellectual disability combined with challenging behaviours provides complexity that is difficult to manage, with serious repercussions for the family unit as a whole and for siblings in particular.

1. THE COMPLEXITY OF ISSUES

Participant families provide support for their child with a disability with the core activities of feeding, toileting and dressing. Most of the children or young people in this study did not have verbal communication and experienced dual physical diagnoses sometimes coupled with mental health issues. Many exhibited more than one challenging behaviour, including aggression, self injurious behaviour, destructive outbursts and sleep problems. Other behaviours which were evident to a lesser extent included breath holding, faeces smearing and inappropriate sexual behaviour.

Families often responded to these behaviours by developing intricate security systems for the safety of the family to a point where one parent considered the family home was like a 'locked down prison'.

2. IMPACTS UPON CARERS

The impacts upon the parent carers of such children ranged from physical health issues such as heart complications and sleep deprivation with physical exhaustion through to a lack of adequate nutrition, eating on the run and fatigue. Parents also reported depression, stress, anxiety and feeling suicidal. They used such words as 'turmoil', 'crazy', and 'stressed' to describe their experience.

Marital relationships also suffered although most in this study still had their marriages intact. Participants spoke of the focus in the marriage being on the child or young person rather than each other and the impact that stress and fatigue had on their relationship. There was evidence of anger and frustration in the outworking of the stress. Most also found that maintaining employment was difficult – particularly women – who required that work be very flexible to meet the unpredictable nature of the care arrangements. Career progression was not an option for most participants and one self-employed parent had experienced bankruptcy as a consequence of his caring role.

For some families, the stress of the caring situation eventually became intolerable. Some parents spoke of the guilt and grief they had to face once they had reached a crisis point and were forced to surrender their child with a disability to the State.

3. IMPACTS UPON SIBLINGS AND THE WIDER FAMILY

One of the most concerning findings from this research was the impact that the caring role had on siblings. They had often witnessed behaviour which was violent, had to have their bedrooms locked, had their personal space regularly invaded and

sometimes resented the time and focus dedicated to their brother or sister with a disability. They did not feel as if they could have friends over during their school years and had difficulty explaining their home life to their peers and friends. Parents expressed guilt at the lack of time spent with their other children, commenting on their child's loneliness, anxiety and stress as a result of the caring roles in the family and, in one case, a mother reported that her child had a complete breakdown.

On the positive side siblings reported that they wanted to achieve a great deal in their life to make their parents proud – and parents observed empathy, compassion and wisdom in these siblings which they felt would hold them in good stead as adults and was the end result of the intense caring experience.

Caring for a young person with an intellectual disability combined with challenging behaviours also had a significant impact on family activities and holidays with most of these activities being seriously compromised. Even important family events had to be planned well in advance without the luxury of spontaneity. Some parents reported feeling isolated and disconnected from their family and friends.

4. CARERS' SERVICE NEEDS

Respite care was considered critical but was seriously inadequate for this particular cohort of young people. Parents reflected on the relatively infrequent access, the degree of advance notice required, the issue of dealing with multiple service providers and the unreliability of the services. They cited being called to take their young person home mid-way through respite because of a physical issue or because the challenging behaviour could not be managed at the site. The short duration of respite meant that staff did not get to understand the complexity of the issues.

There were also particular concerns expressed in relation to medical and dental visits. The young person's inability to communicate or comprehend what was happening, the presence of challenging behaviours, forced waiting in surgeries and the need for the use of sedation or a general anaesthetic made dealing with doctors and dentists not only problematic but also expensive.

5. WHAT CAN BE DONE?

The Kingsdene model is a shared care, residential, educational model which yielded significant benefits both for the young person with disability and for the family unit. There was evidence of improved life skills, sleeping patterns, routines and toilet training for the young person with disability. Parents felt that the young person had been given opportunities to socialise, forge friendships of their own choosing and enjoy a social life in a non-judgemental environment.

As a result of the shared care arrangement parents reported a reduction in their own stress and anxiety, improvement in their sleeping patterns, opportunities to engage in further employment, education and training and new opportunities to reconnect with family and friends. Siblings reported improved parenting, with their parents having more time to spend with them, support them with schooling and after-school and sporting activities. They felt that they, too, had more opportunities to socialise, could bring friends home during the week and further develop friendships.

The success of the model as reported by participants should now be considered in future planning and policy options by Government. The National Disability Insurance Scheme does have the potential to provide families like those who accessed Kingsdene with a flexible funding model which is tailored to meet their very specific and intensive needs. However it needs to reduce the current administrative burden faced by parents, be simple and easy to navigate, provide well trained and caring staff who are adequately remunerated and provide easy access to information and care options.

6. CONCLUSION

This research has highlighted the very complex caring role of families when they have a child or young person with an intellectual disability combined with challenging behaviours. The experience of the caring role has been courageously articulated by these families and serves to endorse a new approach to disability service provision. It is hoped that the new National Disability Insurance Scheme will provide the flexibility and support these families so desperately need.

7. RECOMMENDATIONS

In the light of this new national approach, it is recommended that:

1. The **New South Wales Government** provide funding for the residential special school model, as exemplified by the Kingsdene special school.

2. The **NSW Government** retain block funding of such a model, in part or in full.

3. In implementing the NDIS, the **Federal Government** have special regard to the needs of people with severe and profound intellectual disabilities and their carers, including:

- 'red tape' reduction and consistency in service delivery among providers

- provision of adequately remunerated, well-trained staff

- development of services which know how to assist children and young people who exhibit both significant intellectual disability and challenging behaviours

- a flexible model of service provision to meet both individual needs and the needs of the family as a whole

- easy access to information on services

- access to periodic intensive support services.

4. In providing support packages for people wth an intellectual disability the **Federal Government** through the NDIS take into account the needs of parent carers and siblings. Separate assessment of carer and sibling needs should be undertaken.

5. Both **Federal and State Governments** provide funding for staff training for specific additional skills to work with people with an intellectual disability who also have challenging behaviours.

1. INTRODUCTION

1.1 GROWING UP WITH A DISABILITY IN AUSTRALIA

Approximately four million Australians suffer from some form of disability, according to the Survey of Disability, Ageing and Carers (SDAC) (2009). For the purposes of the SDAC, 'disability' was defined as any limitation, restriction or impairment that restricts everyday activities and has lasted or is likely to last for at least six months (ABS, 2009a:3). Further, the Commonwealth Disability Discrimination Act 1992 (Section 4) defines disability to mean: the total or partial loss of a person's bodily or mental functions or part of the body; the malfunction, malformation or disfigurement of a part of the person's body or differential learning.

About 100,000 children in Australia have an intellectual or developmental disability.

Of the four million Australians with a disability, 5.9% have a disability which is classified as being either severe or profound (ABS, 2009b). Among the 4.29 million children under the age of fifteen years in Australia, 2.6% had an intellectual or developmental disorder.[1] In other words, about 100,000 children in Australia have an intellectual or developmental disability.

Most children with a disability are cared for by family members, usually parents. An Institute of Family Studies study highlighted that seventy percent of the female carers in their study were aged between 36 and 65 years, and 43.5% (or 1,131,000) were looking

after children with a disability (Edwards et al, 2008: 20, 22)

1.2 LEVELS OF CONGENITAL DISABILITY

People with a disability generally have a problem with a core activity such as:

- *Self-care*—bathing or showering, dressing, eating, using the toilet, and bladder or bowel control

- *Mobility*—getting into or out of a bed or chair, moving around at home and going to or getting around a place away from home

- *Communication*—understanding and being understood by others: strangers, family and friends (AIHW, 2008:33).

Four levels of core activity limitation have been defined, based on whether a person needs personal assistance with, has difficulty with, or uses aids or equipment for any of the core activities. A person's level of core activity limitation is determined by the highest level of limitation the person experiences in any of the core activity areas. The four levels of core activity limitation are:

- *Profound*—always needs assistance from another person to perform a core activity

- *Severe*—sometimes needs assistance from another person to perform a core activity, or has difficulty understanding or being understood by family or friends; or can communicate more easily using sign language or other non-spoken forms of communication

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1. Includes intellectual disability, autism and related disorders (Rett's syndrome, Asperger's syndrome), developmental learning disorders and coordination disorders.

- *Moderate*—does not need assistance, but has difficulty performing a core activity

- *Mild*—has no difficulty performing a core activity but uses aids or equipment because of disability; or cannot easily walk 200 metres, walk up and down stairs without a handrail, easily bend to pick up an object from the floor, or use public transport; or has difficulty or needs help using public transport (AIHW, 2008:33).

All of the children in this study fall into the first category where they always require assistance from another person to perform a core activity.

1.3 ANGLICARE AND DISABILITY ACROSS THE LIFE COURSE

ANGLICARE'S disability services across Sydney and the Illawarra encompass programs for both carers and people with disability across all ages. For children there are volunteer programs which involve a host family providing respite to a child with a disability, provision of vacation care to children with a disability, leisure activities for children with a disability, recreation for adults with an acquired brain injury and centre-based and community activities programs for young people with a disability aged 10-18 years during the school holidays. There is also a young carers' program and vacation and after school care for children with a disability as well as integrated family respite for young people under the age of 16 years.

As the largest provider of disability services in western Sydney, ANGLICARE also offers a range of respite programs, both residential and in home, and ageing parent carer programs which support carers over the age of 65 years who are still looking after an adult son or daughter with a disability.

1.4 THE KINGSDENE FAMILIES

The participants in this research project were families who had, at some stage, attended ANGLICARE Sydney's Kingsdene Special School and accompanying Residential Services. The school commenced in 1973 as a specialist weekly boarding school (during the school year) for children and young people with moderate to severe intellectual disabilities.

Kingsdene Special School was a member school of the Association of Independent Schools[2]. The school was registered by the NSW Board of Studies to enrol students with intellectual disabilities and was accredited to deliver Year 7-10 curricula, as required for the NSW School Certificate. It was devolved to the Department of Ageing Disability and Home Care (ADHC) and the NSW Department of Education and Training (DET) at the end of 2010. The reauspiced facility was renamed 'Gibbons Street', and was then run for a further two years by the State Government and finally closed in December 2012.

Students attended Kingsdene (and Gibbons Street) from across a wide geographical area, with most families living in the Greater Sydney area. Kingsdene families were also drawn from a wide range of socio-economic, cultural backgrounds and household types. The age of the students ranged from 10 to 18 years. Students possessed profound intellectual disabilities as well as mobility, speech and communication impediments; visual impairments; challenging behaviours; autism spectrum disorder; medical conditions such as epilepsy, depression, anxiety and other mental illnesses.

These young people had typically been residing with their families until the time of their enrolment at Kingsdene (at the minimum age of 10 years). Each of the families whose children had attended Kingsdene

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2. Within NSW, there are three school sectors: Government; Catholic and Independent. A significant number of independent schools in NSW also operate boarding facilities. There are also 25 special schools in NSW that cater for students with disabilities and other special needs, including for students with severe and multiple physical, emotional and learning disabilities or behavioural issues.

did so for divergent reasons. Families were seeking an environment with programs and resources suited to the specific and individualised needs of their children, provided as a shared care arrangement over each school week.

There were two components to the Kingsdene program:

1. The School component which operated Monday to Friday and did not include weekends or school holidays.

2. Residential care provided over four nights, Monday to Thursday, with young people returning home to the family on weekends and holidays.

This residential boarding school option was seen by parents as providing an intensity of education support not typically available in regular schools combined with respite and consistency of care. This arrangement, by providing a 24 hour service and curriculum, ensured a consistency of programs, facilitating the development and management of students (McGill, Tennyson & Cooper, 2006).

1.5 HOW THIS RESEARCH PROJECT BEGAN

The devolution of the Kingsdene School to government and then its final closure highlighted the significant issues faced by these families once they no longer had access to this type of residential and educational support. It was determined at the time of devolution that the issues and challenges faced by

these families required further exploration, as did the nature of service support required in the post Kingsdene environment. The particular combination of profound intellectual disability and challenging behaviours of the young people meant that these

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There is a need to explore the impact of caring on the quality of life of parents.

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families were confronted with a range of issues which were largely unreported and often misunderstood in the wider community. As Yoong and Koritas concluded:

> *"Given that the current trend in many countries, including Australia, is to keep people with ID [intellectual disability] in their family home for as long as possible (Griffiths & Unger, 1994), there is a need to explore the impact of caring for an adult with ID on the QOL (quality of life) of their parents." (Yoong & Koritas, 2012:610)*

This research project is designed to address this gap in our current understanding. It was considered that the project was likely to reveal that the approach commonly followed in caring for children with an intellectual disability in Australia is having a severe impact on the lives of those involved. It was also thought that the levels of support available to families and the models of care would also be shown to be inadequate – something for which this study provides significant evidence.

2. METHODOLOGY

2.1 KEY QUESTIONS ADDRESSED IN THIS PROJECT

The primary aims of the research were to discover:

- how family care-givers of people with profound intellectual disabilities negotiate the needs of the child with a disability and the needs of the family unit

- how carers cope with and manage challenging and sometime violent behaviours

- the costs and consequences[3] associated with juggling these complex, and sometimes conflicting, needs and the impact this balancing act has on the family unit.

Secondary research questions included:

1. What are the day-to-day implications of caring for a young person with profound intellectual disabilities and challenging behaviours?

2. What impact does having a young person with profound intellectual disability and challenging behaviours within the family have on the physical health, mental health and social functioning of that person's parents and siblings?

3. What impact does having a young person with profound intellectual disability and challenging behaviours within the family have on the family's economic status?

4. What has been the experience of families in dealing with existing service providers, and what improvements could be made to existing services in order to provide the best support and assistance to families in similar circumstances?

2.2 METHODS USED

A qualitative approach was adopted which involved:

1. An extensive literature review of the key challenges faced by families caring for a severely intellectually disabled young person.

2. A scoping focus group, attended by parents and siblings from amongst the families of intellectually disabled young people who had attended Kingsdene School. This group allowed family members to express opinions, based on personal experience, regarding topical areas for exploration within this project.

3. Personal interviews with parents and siblings who were willing to share their experiences.

The literature revealed that while a great deal is known and documented about the nature of challenging behaviours and departmental and governmental approaches to disabilities, very little is known about how families manage and deal with the day-to-day care and struggles of the needs of their families.

In total, 15 participant interviews were used for analysis and reporting. Interviews were digitally recorded for the purposes of later transcription and analysis. Recordings were not used for analysis in two cases: in one interview, because the participant requested that the interview not be recorded, and in the other, due to poor audibility of the recording.

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3. ANGLICARE recognises that 'costs and consequences' are not wholly experienced in economic or financial terms, but rather can be manifested physically, emotionally, socially, relationally and spiritually.

Researchers' written notes provided the material for analysis from these two interviews.

2.3 DATA CODING AND ANALYSIS

Once transcribed, the interviews were coded and analysed according to key themes. Themes included: levels of care required; challenging behaviours exhibited by the family member with a disability; effects on parental well-being; effects on parental employment and finances; effects on siblings; restrictions to social life; availability of services; problems dealing with existing services; advocacy and thoughts about Kingsdene School and future directions in care options. The overall findings from data collection were collated and analysed for this report.

2.4 ETHICS

In the development of this project strict ethical guidelines were followed. All participants were assured of confidentiality and pseudonyms were used for the report. The interviews were conducted sensitively and all participants were provided with an option of counselling support post interview if required. All electronic data pertaining to this project was stored on a secure computer drive, and all paper-based materials stored in a locked filing cabinet to which only the researchers have access. Data will be kept for a minimum of two years from the completion of the project.

Participants were provided with an Information Sheet which outlined:

- Details about the research project, researchers conducting the project, the research design, anticipated outcomes and dissemination plans

- That participation in the research was voluntary, and participants were free to withdraw at any time during the research process

- That all information identifying participants would be kept confidential and pseudonyms or associated strategies would be used to ensure the privacy and confidentiality of participants at all times

- That decisions not to participate would not affect participant relationships with ANGLICARE, ANGLICARE services, staff or related agencies

- How data would be recorded and stored.

Research participants were also provided with a Consent Form outlining their rights and responsibilities and their agreement to participate on that basis. Participants signed and dated the Consent Form, thereby verifying their consent to participate.

3. THE YOUNG PERSON PARTICIPANT COHORT

Although there is some variation in the level of physical and cognitive ability amongst the children and young people who were part of this research, they all typically require high levels of physical care. They are often non-verbal, making communication and attending to daily needs more difficult. In addition, a large number suffer from medical conditions such as epilepsy, depression or other mental illnesses. The type of intellectual disabilities typically found among the Kingsdene children are outlined in the Appendix and are discussed in this section of the report.

3.1 LEVEL OF FUNCTION IN ACTIVITIES OF DAILY LIVING

Research participants were asked about the level of care required by their child or young person with an intellectual disability on a daily basis. Although the young people are aged from mid-teens to mid-thirties, their level of intellectual disability generally means that the level of daily care required is equivalent to the care required in the first two years of life of a typically-developing child.

Very few of these young people have verbal communication skills.

The parent interviews revealed that many of the young people need assistance in feeding themselves and are unable to toilet themselves independently. Other daily self-care tasks such as washing and dressing are beyond the reach of most of these young people. The following are some typical examples of their situation:

Simon is still wearing nappies. (Letitia, mother)

Peter can use a spoon but like a nine month old… it needs to be an appropriate consistency of food… (Margaret, mother)

We have to lay his clothes out for him and help him with his dressing. (Christine, mother)

In addition to the assistance required for basic activities of daily living, many of the young people have physical health or mobility problems. Epilepsy is the most common medical condition found amongst the group:

Because when she's had the major seizures, you know, sometimes it knocks her out... then she wakes up and just goes straight into another major seizure. (Daniel, father)

Epilepsy medications must be administered daily by the parents; these can cause side effects, and sometimes the process of finding the most effective combination of medications may take years of trial and error.

Very few of these young people have verbal communication skills. Physical ailments, even if minor, are complicated due to the children's inability to communicate with their parents. These young people, then, need constant supervision in order to prevent harm to themselves or to others. This task has fallen to their parents, primarily, and in a secondary way to their siblings. One of the biggest problems is where the young person has independent mobility but without the cognitive awareness of potential dangers:

He would be more than happy to walk out into the middle of a busy road… (Margaret, mother)

…you can't have an open door or anything because he'll just go… (Kathryn, mother)

…you have to be with him all the time…(Evelyn, mother)

3.2 CHALLENGING BEHAVIOURS

The presence of challenging behaviours among children with intellectual disabilities is now widely acknowledged within the contemporary disability literature. Many authors refer to the definition formulated by Eric Emerson in 2001, who stated that challenging behaviour is:

"Culturally abnormal behaviour(s) of such intense frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities" (Emerson, 2001, p3).

There are many interchangeable terms used within the literature and disability sector to describe this behaviour. 'Challenging' is the most common term, but terms such as 'aberrant', 'atypical' and 'disruptive' have also been used.

Embregts et al (2009) examined challenging behaviours among residents of facilities in the Netherlands, suggesting that challenging behaviours serve the following purposes: attention-seeking; avoidance of unpleasant situations; stimulation of self; and acquisition of tangible rewards. Others have proposed that challenging behaviours can be attempts to avoid unpleasant situations, are possible defence mechanisms, or are a means of obtaining desired objects (Dossetor, 2011; Reese et al, 2005).

Challenging behaviours may also occur because the person with an intellectual disability often lacks the appropriate skills to deal with life stressors. Poor coping mechanisms often result in the further

manifestation of challenging behaviours (Adamek et al, 2011).

There are five behaviours which consistently appear in the literature under the heading of 'challenging'. In order of prominence in the literature, these are: aggression; self-injurious behaviours; destructive behaviours; stereotypies[4], and sleep disorders. Each of the families interviewed from the Kingsdene School has faced some degree of challenging behaviour as exhibited by their young person, with all five forms of challenging behaviours being reported.

3.2.1 Aggressive Behaviour

Aggression is the single most important subset of challenging behaviours in terms of its frequency of occurrence in the literature, and includes both verbal and physical components, which may be directed against staff or other residents (if the person is in residential care) or against parents and siblings in

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> ### *The prevalence of aggression among persons with an intellectual disability range from 39.5% to 87.5%.*

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the home situation (Dominick et al, 2007; Bihm et al, 1998). Statistics concerning the prevalence of aggression among persons with an intellectual disability range from 39.5% to 87.5% and can vary according to the type of intellectual disability (Oliver et al, 2011; Sloneem et al, 2011; Lowe et al, 2007).

The precipitating factors for aggression are not entirely certain. The diagnosis of autism has been demonstrated to be associated with aggression in a meta-study of the literature on intellectual disabilities (McClintock et al, 2003), as well as in more recent studies where information has been gathered first-

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4. 'Stereotypy' is defined as a motor disorder which is repetitive (American Psychiatric Association, 2000).

hand (Matson & Rivet, 2008). It is generally agreed that aggression occurs because other means of communication are underdeveloped; for example, children who have autism demonstrate poorer adaptation to new situations and because they do not possess sufficient communication or social skills, become aggressive when challenged by the situation (Oliver et al, 2011; Shattuck et al 2007). Aggression may also be displayed to obtain a desired object (Reese et al, 2005).

It is distressing for carers to experience violent acts against themselves or others.

It is also thought that physical problems may lead to aggressive behaviour. For example, urinary incontinence and visual problems have been cited as producing levels of frustration leading to aggression among people with an intellectual disability (De Winter et al, 2011). Lower levels of physical ability, however, are associated with lower levels of aggression; it is thought that more physically disabled people are less capable of producing the movements required in order to be physically aggressive (Bihm et al, 1998; Poppes et al, 2010).

Whatever the cause, it is distressing for carers to experience violent acts against themselves or others. One study showed that violent acts committed by persons with an intellectual disability can occasionally result in police involvement (Crocker et al, 2006) or the victim needing medical assistance (Tyrer et al, 2006).

Aggressive behaviour has, until recently, been underrepresented in the intellectual disability literature, possibly because it has been considered an "emotionally charged term" resulting in pressure to avoid using it (Farmer & Aman, 2011). However, given the prevalence of aggression among people with an intellectual disability, it is a vital area of concern for carers in particular, who are the witnesses

and sometimes the victims of aggression, as well as clinicians and policy makers.

Aggressive behaviour, manifesting as physical violence, has been experienced by ten of the fifteen families represented in this research. The following quotes from the parent carer interviews provide examples of the severity of injuries to carers and family members caused by incidents of aggression accompanied by physical violence on the part of the person with a disability:

> *He would 'ragdoll' me … he would smash me in the face and my glasses would cut my eyes. (Elizabeth, mother)*

> *Mum [Joel's grandmother] decided to come around … she's quite tiny and he pushed her and she fell over and broke her hip and her elbow. (Sally, mother)*

> *… the carers and the family members … have been hit, been bitten. (Phillip, father)*

> *Biting or hitting people in the head … one of the more likely places for it to happen is sitting in one of the vehicles of Community Access and what he would do is bite the head of the person in front. (Eileen, mother)*

> *The difficulty was also when we would have people over and in particular if he would attack cousins and grandparents. (Hugh, father)*

Sometimes the apparent aggression was actually child-like behaviour which became injurious because it was expressed by adult-sized bodies:

> *… he's so affectionate … he can only take one step before he's got someone else in a deadlock … (Margaret, mother)*

> *He's not aggressive but because of his size his actions can be … his challenging behaviour is hugging … (Sally, mother)*

At the same time, it is important to note that some of the young people in this study were not capable of engaging in affectionate behaviour. This is a hard reality for many parents:

That's the hard thing, that they don't have that: the others will come and say "I love you Mum."(Janice)

3.2.2 Self-injurious Behaviour

Self-injurious behaviour is the next most frequently recognised 'challenging behaviour' and involves acts of aggression committed by the person with an intellectual disability against him or herself. Manifestations of self-injurious behaviour can include head banging, hitting and biting oneself and also unpleasant behaviours such as the consumption of inedible materials and making oneself vomit (Dominick et al, 2007; Emerson et al, 2001). Again, self-injurious behaviour has been strongly associated with diagnoses of autism (Dominick et al, 2007) and with greater levels of intellectual disability (McTiernan et al, 2011). Whilst it is a key part of challenging behaviour within the disability discourse, self-injurious behaviour did not form a dominant part of the lives of the families involved within this research. In fact, only three of the young people were reported to have engaged in behaviours that resulted in self-inflicted injury:

He picks his skin so he'll just sit and pick and pick and pick … (Christine, mother)

Megan would bite herself out of frustration. (Elaine, mother)

She could start biting herself. She never used to try to bite me … but she would start biting herself and jumping up and down and screaming. (Matthew, brother)

3.2.3 Destructive Behaviour

Destructive behaviour is defined within the research as 'acts of aggression towards or involving inanimate objects'; for example, throwing items across the room or destroying property (Saxby & Morgan, 1993; Shattuck et al, 2007). The prevalence of this type of behaviour among people with an intellectual disability is approximately 30% (Oliver et al, 2011:5; Shattuck et al, 2007:1743). Destructive behaviour can result in injury and harm to others. Some of the parents and a sibling interviewed for this study gave the following descriptions of destructive behaviour:

He has ripped up untold certificates [and] untold photographs … (Kathryn, mother)

He'll go around the house … pouring juice and cream [everywhere] … (Letitia, mother)

… this table was overturned, the leg on the table had broken off, the chairs were all upturned, there was food all over the place, broken glass everywhere and Ben was sitting in the middle of it … (Evelyn, mother)

…. in the gyprock wall, he makes holes … (Phillip, father)

3.2.4 Sleep Problems

It has been found that sleep problems may occur in as many as 77% of people with an intellectual disability and that there are positive correlations between sleep problems and the presence of other challenging behaviours (Rzepecka et al, 2011).

The incidence of sleep problems among the young people within this project was described by each of the families as having been present, to some extent, during their child's entire life. Some children simply do not sleep for long hours, some have disturbed sleep due to epilepsy, and some wake, remaining alert for large portions of the evening, and therefore require constant observation and monitoring. Among participant families there were examples of whole nights where parents would not sleep, or would 'tag team' with each other through the night:

… the whole night he didn't sleep; my husband had to go to his room to put the mattress [against the door] and sleep[there] so that he won't open the door … (Letitia, mother)

When he was at home he would wake up several times a night and not go back to sleep … so my parents had to 'tag team'. (Rachel, sibling)

… he was on a manic high night after night, unable to sleep and one of us, either of us would take it in turns … to try and stay with him and make sure he was not hurting himself and try and calm him down so he could go to sleep at night and he'd be 'laughing' to the point where he can no longer breathe and this was sort of one, two, three o'clock in the morning. He'd collapse with exhaustion and you'd be in the room with him all that time and then you're up and get ready go to work the next day. (Ross, father)

Most parents in this study have also attempted to maintain full-time employment as well as family responsibilities while experiencing severe sleep deprivation.

3.2.5 Stereotypies

Stereotypies, or repetitive behaviours such as hand flapping, are common amongst people with an intellectual disability, with a prevalence rate of between 49% and 82% reported in the literature (Poppes et al, 2010; Saxby & Morgan, 1993).

While identified within Emerson's (2003) operational definition of challenging behaviour, stereotypies were less common and apparent within the lives of the families involved in our research. In fact, only two of the parents interviewed made mention of such behaviour:

Lucy's a Rett[5] so they have these hand movements … (Janice, mother)

He does the repetitive rocking and if he happens to be sat on a chair which has a sharp edge where his back lands he can bruise his back. (Ross, father)

These behaviours may, as in Lucy's case, cause embarrassment if the behaviours occur in a public place. In the case of Ross' son, the rocking becomes a form of self-injurious behaviour, causing additional distress for other family members.

3.3 FURTHER CHALLENGING BEHAVIOURS

There are a number of other behavioural attributes of people with severe intellectual disabilities including eating disorders and temper tantrums (Dominick et al, 2007) and uncooperative behaviour and withdrawal (Shattuck et al, 2007).

"We were dealing with incontinence and bed wetting and defecation randomly around the house"

In this research, parents and siblings reported a range of atypical and inappropriate behaviours which included breath holding, taking food from others, being noisy and unpredictable, bed wetting and faeces smearing:

… if he sees something he wants like [someone else's] food on a table in a food court he'll just go up and take it … (Rachel, sibling)

… the biggest challenge is she's a breath holder … (Tammy, mother)

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5. Rett Syndrome is a genetic disorder in which children develop microcephaly, autistic features and various stereotypical hand movements such as patting, beating or clapping. Between 70-80 % of people with Rett Syndrome also suffer from epileptic seizures (Brain Foundation, 2012 Ibrahim & Khan, 2008).

James is extremely loud … and very much in your face. (Christine, mother)

… we were dealing with incontinence and bed wetting and defecation randomly around the house and it being used as a tool when we would discipline Shane. (Hugh, brother)

Such challenging behaviours can metamorphose as the young people grow older. When these children begin to reach puberty, their inappropriate behaviours can incorporate sexualised actions and behaviours, both in the home and in public and both with family members and strangers.

… sometimes you know silly sexual stuff, pushing against people … (Amelia, mother)

… he may pull down his pants and show his genitals in public … (Phillip, father)

She could strip off naked. (Matthew, sibling)

One father, Phillip, recounted an incident where he had to explain to police officers, summoned by bystanders (offended by his son's indecent exposure), why his child was acting the way he was, and why he was recalcitrant despite Phillip's best intentions. Many of these young people do not physically *appear* to have a disability, so members of the community are often misled about the nature of their atypical public behaviour. Such challenging behaviours meant that some families felt socially restricted and not able to take the young person with a disability out in public. This effect is recognised in the second part of Emerson's definition of challenging behaviours: "*behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities*" (Emerson, 2001, p3).

4. IMPACTS OF FULL-TIME CARE ON PARENTS

There are a number of impacts on parents caring for children with profound intellectual disabilities combined with challenging behaviours. These range from physical and mental health, to employment and financial deprivations. This chapter explores more fully those impacts as described in the literature and by the participant families in this study.

4.1 PHYSICAL HEALTH

The physical health of parents has been demonstrated, in studies conducted both in Australia and overseas, to be adversely affected when there is a child with an intellectual disability in the family. In a study conducted by the Australian Institute of Family Studies (AIFS), it was found that carers' health is adversely affected at an earlier age than non-carers' health (Edwards et al, 2008).

This finding is supported by another Australian study which found that the incidence of a variety of physical problems is significantly higher amongst the carer population than in the general population. The same study found, more specifically, that carers are twice as likely as non-carers to suffer high levels of pain, and also that carers are more likely to be carrying an injury (Australian Unity, 2007). The Australian Unity study noted that carer health levels were the lowest values ever recorded for a large group (Australian Unity, 2007:44).

Various stressors have been identified in the literature as having negative effects on parents' physical health:

- Caring for someone with a high level of care needs (Edwards et al 2008)

- Caring for more than one person with a disability (Edwards et al, 2008)

- Caring for someone with behavioural problems (Khanna et al 2011)

- Caring for someone with regularly disturbed sleeping patterns (Lopez-Wagner et al, 2010)

- Not receiving enough support in the caring role (Edwards et al, 2008; Khanna et al 2011)

- Poor family functioning levels (Edwards et al, 2008; Khanna et al 2011)

- Inability to attend to one's own health needs due to time constraints or lack of respite care facilities (Australian Unity, 2007; Murphy et al 2006)

- Inability to pay for one's own health needs (Australian Unity, 2007).

When questioned about their state of health, the parents interviewed reported a variety of physical conditions which they attributed directly to the years spent caring for their children. These physical ailments included dental issues and heart problems. Sleep deprivation and a lack of adequate nutrition because of difficulties at meal times were also mentioned:

I would be lucky if I can sleep four hours straight a night... And I can't fall asleep; I find it so, so difficult and I know it's bad for me. (Elizabeth, mother)

...they [her parents] were frightened of falling asleep at the wheel because they were so sleep deprived. (Rachel, sister)

I've trained myself to eat only one a day, one meal a day ... no energy to work...I've been training years and years and years like this. (Phillip, father)

4.2 MENTAL HEALTH

Significant research has been conducted in the area of carers' mental health. Faust and Scior (2008) conducted semi-structured interviews with the parents of autistic children; their phenomenological analysis of the interview transcripts yielded many strong descriptors of a lack of emotional wellbeing, such as 'struggle', 'pressure', 'prisoners', 'helpless' and 'isolation' . In a web-based questionnaire inviting written answers from almost five hundred parents of children with diagnoses on the autism spectrum in English-speaking countries (including Australia), other descriptive language such as 'dismal' and 'grief' emerged, as well as an overarching statement: 'autism has overtaken *everything* in the family's life' (italics in original) (Myers, Mackintosh and Goin-Kochel, 2009).

Australian research has shown that carers have a mental health status which is significantly worse than that of the general population and that, within the caring population, female carers have significantly worse mental health status than their male counterparts (Edwards et al, 2008). In numerical terms, Australian carers are 1.42 times more likely to be at risk of developing depression than the general population (Edwards & Higgins, 2009).

AIFS researchers found that care of a child with a disability is more stressful than, for example, care of an aged parent or of a partner (Edwards et al, 2008). A diagnosis of autism results in higher rates of reported mental health problems among parents. For example, in a study comparing the mental health status of parents of autistic children with that of parents of Down syndrome children, the rates of mental health problems were significantly higher amongst the parents of the children with autism (Hamlyn-Wright, Draghi-Lorenz & Ellis, 2007).

Walden, Pistrang & Joyce (2000) found that the level of challenging behaviours present in the child is the strongest indicator of the presence of depression and/or stress in the parents. Similarly, Lecavalier, Leone &

Wiltz (2006) stated that challenging behaviours, more than any other characteristic of the child, are associated with increased stress levels in the parents, and that those behaviours and the parental stress then exacerbate each other in a downward spiralling effect.

> ### *Carers have a mental health status which is significantly worse than that of the general population.*

A child or young person with challenging behaviours requires constant monitoring (Faust & Scior, 2008), meaning that other aspects of the parent's life are neglected or ignored altogether, resulting in stress. This vigilance is necessary even during the night, which results in sleep deprivation for the parents, which in turn results in increased stress and both mental and physical fatigue (Gallagher, Phillips & Carroll, 2009). Parents report that the unpredictable nature of the challenging behaviour causes tension , as parents constantly worry about what the child will do next (Tehee, Honan & Hevey, 2009).

There may be a pre-existing physical health problem in one or both parents which is totally unrelated to the birth of a child with a diagnosis of intellectual disability. In a large-scale secondary analysis of Australian data, it was found that the physical health status of the mother is an important factor in assessing the risk of psychological distress in those mothers (Emerson & Llewellyn, 2008). A more recent study involving mothers of children with a disability in Victoria found that when a parent has a physical health problem and is caring for a child with a disability, their mental health assessment score is significantly lower than for those with good physical health (Bourke-Taylor et al, 2012).

The family's situation, in a number of contexts, has also been demonstrated to have a bearing on parental mental health status. There are, sometimes, simple

factors involving family composition which have been shown to be detrimental to mental health status. For example, having another child who is of pre-school age has a significantly detrimental effect on the mental health of mothers of children with a disability (Bourke-Taylor et al, 2012).

Australian research has found that "*approximately 50% of the elevated risk of distress could potentially be attributed to increased rates of poverty among children with a disability and their families*" (Emerson and Llewellyn, 2008). While only one of the families in this research cohort has suffered significant financial losses as a result of having a severely intellectually child with a disability, previous research has also shown that mental health problems, resulting from parenting a child with an intellectual disability, may still occur in parents who have financially stable economic situations (McConnell and Llewellyn, 2006).

A number of extraneous factors have been listed within the literature as exerting a negative effect on parental mental health. These include:

- Difficulty in dealing with service providers (Myers, Mackintosh & Goin-Kochel, 2009; Edwards et al, 2008)

- Lack of support from family and friends (Khanna et al, 2010; Edwards and Higgins, 2009)

- Concerns regarding the public acceptability of a child with a disability with challenging behaviours (Higgins, Bailey & Pearce, 2005).

In the ANGLICARE research, the participants described their mental health in a variety of ways. Some spoke of stress and turmoil, while others used terms such as 'depressed', 'crazy' and feeling like they were 'not coping'. The following quotes are typical of the feedback received from participants in the ANGLICARE study:

Oh, I'd say, I feel stress daily. She walks in the door and my stress level will go up. (Janice, mother)

I mean your sort of life's in turmoil really. (Mark, father)

I'm depressed because I feel at times that I can't change my situation. (Evelyn, mother)

Several parents described their lives as being tethered to their child with a disability.

More seriously, one parent spoke of feeling suicidal as a result of her caring responsibilities:

You know I came so close to taking my own life because that was just another thing that added to all that …you know that lack of self worth and you know what am I doing here and you know those terrible thoughts that you have. I mean look, all parents, I'm telling you now, all parents who have kids like ours go down those really dark places, they do. (Elizabeth, mother)

I was going to commit suicide and take Shane with me, I had it all planned and everything. (Elizabeth, mother)

Several parents reported difficulties in dealing with other family members as a result of their mental stress, as they appeared difficult and constantly on edge:

And the other children would see it as me just being a cranky, depressed bitch. (Margaret, mother)

So you get really cranky. (Kathryn, mother)

Several parents described their lives as being tethered to their child with a disability, with a sense of both claustrophobia and isolation:

We're in this little box. We can't leave before Lucy goes [somewhere] and we have to be back before she gets [back]. I have lived my whole life in this box! (Janice, mother)

Stress is also exacerbated with feelings of inadequacy in relation to parenting other children in the household. Some expressed feelings of guilt at not being able to attend school functions or being as supportive of their other children in their schooling. Some felt as if they had either abandoned or neglected their other children to care for the young person with a disability:

... well I know I wasn't able to be as involved in his schooling in his earlier years it wasn't as easy. I mean I tried obviously. (Christine, mother)

... and then Hugh was virtually neglected you know. And then it was sort of like we virtually abandoned Hugh. (Elizabeth, mother)

4.3 MARITAL RELATIONSHIPS

There is little available statistical information in Australia regarding the marital status of parents of children with an *intellectual* disability. However, the number of single parent families (30%) among the cohort of carer families in Australia is higher than in the general population (14%) (FaCHSIA, 2011). AIFS have found that even if separation or divorce was not the end result, more than half of carers reported significantly higher levels of disputes with their partners in their relationship since assuming a caring role (Edwards et al, 2008).

The literature concerning marital relationships yielded a number of factors which lead to an increased risk of marital problems occurring. Risdal & Singer (2004) concluded that the presence of a child with a disability in a family has a negative overall effect on the parents' marriage, although they do point out that the extent of that effect can vary greatly from family to family, depending on family circumstances.

Studies indicate that a child with a chronic or long-term disability will have a greater negative effect on the parents' marriage (Berge, Patterson & Rueter, 2006), compared with a child with a severe illness or a child with multiple health problems (Wei & Yu, 2012). Additionally, when parents are driven to a state of crisis (usually, when a decision is made to seek respite care for their child), the likelihood of parents separating increases significantly (McCoyd, Akincigil & Paek, 2010).

In the literature concerning children with an intellectual disability, the most commonly noted risk factor for marriage relationships among parents is the presence of challenging behaviours in the child. Benson & Kersh (2011), for example, found that there is a significant relationship between behaviour of the child and quality of the marriage relationship among parents of children with a diagnosis of autism.

Mothers of children with an autism spectrum disorder, for example, have reported significantly lower levels of support from their spouses, and lower levels of respect for their spouses, when their children's behaviour problems were at higher levels (Brobst, Clopton & Hendrick, 2009). In a review of the existing literature on this topic, Heinrichs et al (2010) found that when a mother has a child with behavioural problems, she will report significantly lower levels of satisfaction with her marriage than other mothers, and that these findings are directly linked with levels of mental health among these mothers.

Research has also demonstrated deleterious effects on fathers; in a five year longitudinal study of parents with chronically ill children, significant negative associations between paternal depression levels and marital satisfaction emerged (Berge, Patterson & Rueter, 2006).

Of the fifteen families represented in the ANGLICARE study, only two did not have both parents present within the family home. In one of these families, the parents had divorced and the

mother had the children living with her, while in the other, the father no longer had contact with the family and had not done so for many years.

Having a child with a profound disability can mean that the child is the focus of their relationship:

Our whole lives revolve around Lucy really, so that's all we do talk about, you know. (Daniel, father)

… and it's really sort of like a readjustment on our marriage and our relationship and stuff like that and you just don't realise how far apart you are. (Elizabeth, mother)

One parent reported animosity between herself and her spouse:

And so he gets really shitty over it and he'll pick a fight and he'll start screaming at me and I just ignore it. I ignore him when he screams at me, I just do whatever I'm doing and just shut it out … And then it gets to the point where he says "I want a divorce", I say "Fine, get lost". (Evelyn, mother)

Others spoke of greater effort being required to maintain the marriage relationship, and the feeling that they simply have not been successful in having the relationship they would like to have:

Yes, truly there is a lot of sacrifice in the family member, otherwise we can't, you know we can't bear it. We've got to be honest. (Phillip, father)

And strains on the relationship …and just trying to balance it all. Still you never feel like you're doing a good job. (Sarah, mother)

So, while most of the marriages in this sample are intact, the husbands and wives are labouring under much heavier loads than people who do not have children with an intellectual disability:

Oh, it's exceedingly stressful. I mean I suppose that's why so many couples split up. I mean it's a shattering

experience. So no, I think it's very stressful on any relationship. (Kathryn, mother)

One participant, however, thought that the experience had strengthened the relationship as they presented a united front:

… as far as relationship I think it has become a lot stronger. That you need both of us, it's like teamwork. Yeah. So it is continuous teamwork that we've got to do. (Tammy, mother)

4.4 EMPLOYMENT

Recent figures (ABS, 2009a) show that there are 2.6 million carers (of any kind) in Australia. The 2009 report *Carers and Employment* states that in 2003, 61% of carers aged between fifteen and sixty-four years were employed, as opposed to 74% of non-carers in the same age bracket (ABS, 2009c). Carers are, by the nature of their caring responsibilities, more restricted in job choice than non carers; even those with less than five hours of caring duties each week are less likely to have work than non-carers (Bittman et al, 2007). However, those carers who do find employment are faced with many difficulties in their employment situations.

The current legislation in NSW encourages more flexible employment, suggesting changeable start and finish times, job sharing and home-based work are viable options. Carers are entitled to ten days paid leave, two days unpaid leave and two days compassionate leave per year (NSW Department of Industrial Relations, 2010). Employment practices however are often not flexible enough to allow carers to fulfil both roles (Gray et al, 2008), with carers stating that there is a lack of understanding of their situation by both employers and work associates, and that more leave allowances are a high priority need of carers in employment (TOCC, 2007). Research in the US has found that fathers of children with a disability are less likely than their peers to be promoted than other males (Parish et al, 2010).

Lack of care options for the child, health problems suffered by carers which have occurred as a direct result of their caring, and disruption to the life and routine of the child with a disability when the mother goes to work, increases the likelihood that the carer will not be employed (Gray and Edwards, 2009; Gray et al 2008). As the period without employment lengthens, carers become less able to return to the workforce because they lag behind their non-caring peers in areas such as skills development and job confidence (Yeandle, 2011).

Whether employed or not, the literature demonstrates that carers face financial disadvantage in comparison with their peers. Australian research has shown that income for those classified as intensive carers is 20-30% lower than for non-carers , although no specific reasons for this difference were postulated other than that only 10-15% of intensive carers had full-time employment (Bittman et al, 2007). A study by Access Economics in 2005 estimated the annual loss of potential income by Australian carers to be $4.9 billion per annum (Bittman et al, 2007). Figures from the Australian Bureau of Statistics (2008) reveal that, in 2003, 60% of families with a child with a disability had incomes in the lowest two quintiles, compared with 42% of families with no child with a disability.

The employment situation of carers has an effect on more than just the family's regular income. Carers have less superannuation than non-carers; ABS figures for carers aged from 35-54 years show a gap of $9000 in comparison with non-carers (ABS, 2009c). Whether faced with reduced hours of work or with being unemployed, carers may lose the non-financial benefits of work as well. The social interaction of the workplace, where friendships form and self-image is boosted, may be diminished or lost (ABS, 2009c).

The issue of employment poses many problems for carers and deserves the attention of both researchers, who have the ability to further describe the extent of the needs of the caring community, and governments, who need to address the issue of financial hardship of carers. As a group, it has been estimated that carers

actually save the nation $30 billion dollars each year, which is the cost of providing professional, paid carers instead of informal caring arrangements (ABS, 2009c).

The employment situation varies among the families in the ANGLICARE study: most often, the father is employed full-time, while the mother has either reduced hours of work or ceased employment altogether in order to become the primary carer for the young person with a disability. For the mothers who are able to be employed, the nature of their work is limited; they must find a job which allows the flexibility required by their role as primary carer:

My job got threatened. (Sarah, mother)

... one of the things about having a child with a disability is that very few people actually can go to work. (Evelyn, mother)

I think if I'd been in another work place I wouldn't have been able to keep going. (Eileen, mother)

There is little opportunity for career advancement as the need for flexibility by the carer and the unpredictable demands made by caring for these children does not allow for a focus on a career:

I have never bothered to progress myself …in my profession. I keep it at a lower level. My main concern is I need to able to walk out when there's an emergency. (Tammy, mother)

For the fathers, having a child with a disability means they are required to provide not only for the usual requirements of a family, but also for the additional, specialised needs of that child which can create a significant financial burden:

I said to my husband when Shane was diagnosed with a disability, I said "You go to work because we're going to need a lot of money to help this child." (Elizabeth, mother)

Men in full-time employment often do not have the flexibility to take time off and relieve their wives of caring duties:

> If we get a phone call and I've got a day of work and I ask my husband "Can he take time off work?", well he's the major income earner. Unfortunately, it's one of those things where it's all or nothing. (Margaret, mother)

Some, despite the difficulties, made a conscious decision to work, recognising the benefits of being in a different environment for a few hours at a time, providing them with distraction, a sense of identity and achievement:

> I could go out and complete or participate in a job and be me rather than Jordan's mother. So I got that recognition ... it was out of the house. (Eileen, mother)

Some of the fathers, especially those who feel so overwhelmed by the care needs of their child with a disability that they are unable to cope with being in the home, work additional hours to avoid being at home longer than necessary:

> My husband is there but he's working and I think ... working late hours and I think it was his ... in his own business. And that was his way of coping with the whole situation. (Sarah, mother)

Three of the fathers in this cohort are involved in primary care-giving: one because he has retired from full-time employment (Daniel) and another because he was already in a job which allowed flexibility (Mark) and has stayed in the same situation. Phillip has been forced out of the workforce completely due to the demands of caring.

4.5 ECONOMIC AND FINANCIAL IMPACTS

The Australian Institute of Health and Welfare (AIHW) has reported that people living with an income in the most disadvantaged quintile were at least twice as likely to have someone in the household who is severely disabled than those with an income in the most advantaged quintile, in every capital city in Australia (AIHW, 2009). Some researchers believe that the socio-economic status of the family (and not the presence of a child with a disability) is the most important factor affecting the mental health status of the parents. Once a family is living in a state of poverty, additional family factors have been demonstrated to increase the likelihood of the family remaining at the same or a higher level of financial difficulty: the number of dependent children in the household, the health status of the person who is the family's primary source of income, and the employment status of the primary source of income (Emerson et al, 2010).

Families of children whose disability was diagnosed early (which would include most children with a genetic or hereditary disability) have been shown to face a greater degree of financial difficulty (Burton & Phipps, 2009). Similarly, families of children with a severe level of disability face greater economic hardship, as do those whose children's disability is long-term (Doran et al, 2012; Burton & Phipps, 2009,). Costs have also been shown to increase as the child grows older with increasingly complex health issues (Barrett et al, 2011).

Finally, the families of children who exhibit challenging behaviours face higher financial expenditure: specifically, children with self-absorbed behaviour, problems with communication and disruptive behaviour were found to incur greater financial costs than children without challenging behaviours (Einfeld et al, 2010).

Doran et al (2012) found that, in Australia:

- People with an intellectual disability make an average of 25 to 45 visits to some form of care services within a six month period (depending on severity of disability)

- Families devote huge amounts of time (52-61 hours per week for those with mild or moderate disability level and up to 85 hours per week for severe disability level) providing care for their family member with a disability

- Average out-of pocket expenses for a six month time period are more than $12,000

- The value of the time spent by families in caring ranges from $32,000 to $52,000 for a six month time period

- The total financial loss experienced by families in that time period is between $37,000 and $58,000.

It was concluded that by combining the estimated total cost per annum to all families with a family member with an intellectual disability, with the estimated total government expenditure on services and support per annum: the result is an approximate total cost to the Australian nation of $14,720 billion per annum, the bulk of which (over $11 billion) is borne by the families.

Several parents within the participant group in ANGLICARE's study, commented on the extra financial load which had to be borne as a result of the presence of a young person with a disability in their households, including the lack of superannuation:

... I've only just re-entered the workforce so you know, that's been a huge financial impost on the family. I've got no superannuation. For the last twenty years I've been not contributing to the family income at all. (Margaret, mother)

If I had been able to work for those twenty years we'd be in a totally different financial situation. (Kathryn, mother)

I can't tell you how financially draining it is to do what we do. (Elizabeth, mother)

For one parent, Phillip, the care requirements have been so great, that he and his wife have experienced bankruptcy:

I used to be a very successful business person. And I sacrificed more and more and more and more and instead of building up the business I pulled out, pulled out, pulled out and one day I couldn't pay my mortgage. Then I lost two commercial properties in one hit last year, early last year I lost two and finally I had to sell my own house to satisfy people, to pay the bank, to pay back to the bank. Two years ago, sorry two months ago, I haven't got enough money to pay the Taxation Department and I've been declared bankrupt.

While Phillip's situation is the most severe among the research cohort, all of the families represented are restricted in the potential income they may earn as a result of having a child with an intellectual disability, yet they have many additional expenses.

Families of children with a severe level of disability face greater economic hardship.

Items such as nappies (which some of these children have required for twenty years) and medications for conditions such as epilepsy were listed as being required items for regular purchase. Others require specialised equipment such as a wheelchair (Lucy and Gloria) or a hospital bed and hoist (Lucy). Basic needs, for example dental work, become even more of a strain for these families, as the children require a general anaesthetic to be administered in order to have problems addressed:

And with the dental treatment normally with general anaesthetic and each time it costs us five to six thousand dollars. Yes because the treatment can be up to you know fourteen, fifteen teeth at the same time. The reason is, you know, it's funny we've got the private fund, but the private fund has a certain

dental spending limit per year. We may not use it for three, four years but in one year, a lot. We got about four or five hundred dollars refund. (Phillip)

The experience of parents in the ANGLICARE study has been that private health insurance does not allow for the extra requirements needed by these young people; the cost must be borne solely by the parents.

5. IMPACTS ON SIBLINGS AND THE FAMILY UNIT

5.1 SIBLINGS

The sibling relationship can be a critical one. It has been observed that interactions between brothers and sisters provide children with their first socialization experiences (Turnbull, 2006, cited in Meadan, Stoner & Angell, 2010, p 84). Siblings may be best friends, playmates, and soul mates or competitors, mentors or mentees, nurturers or nurtured, the ones with whom to fight or settle conflict, and positive or negative role models (Abrams, 2009, p 307). Every sibling relationship is a mixture of conflict and satisfaction.

Several studies posit that the socio-economic position of the family will affect the siblings of children with a disability, with those from financially deprived families experiencing more relationship stress than those from more financially secure families (Meadan, Stoner and Abgell, 2010; Petalas et al, 2009; Macks and Reeve, 2007). In a large scale research study conducted in the US, Neely-Barnes and Graff (2011) found the importance of the family's socio-economic status as a factor affecting the sibling relationship.

There are a number of factors which can impact the sibling relationship with a child with a disability. These include:

1. **Family structure** - The birth order of the siblings plays a role; being younger than the child with a disability can have a deleterious effect on development of the sibling. When the sibling with a disability is older than their brother or sister, they are more likely to have a difficult relationship with each other (Petalas et al, 2009; Hodapp and Urbano, 2007; Rivers and Stoneman, 2003).

2. **Gender of the sibling without a disability** - In studies involving siblings of adults with an

intellectual disability, it was noted that when the typically developed sibling is female, they are more likely to have a closer and more positive relationship with their sibling with a disability than their male counterparts (Heller and Arnold, 2010).

3. **Gender of the sibling with a disability** also has an effect, with those with brothers with a disability having more difficulties in their sibling relationships than those with sisters with a disability (Hastings, 2007; Petalas et al, 2009).

4. **Severity of disability** - Those with siblings with profound or severe levels of disability display less warmth toward those siblings than people whose sibling has a mild disability (Doody et al, 2010).

5. **Level of functional capacity** - Having a sibling with a disability who is reasonably independent with self-care tasks leads to a more positive sibling relationship (Orsmond and Seltzer, 2007; Sharpe and Rossiter, 2002).

6. **Presence of an autism spectrum disorder** – Has been demonstrated to exert a negative influence on sibling relationships. In a review of twenty-three studies in the area, this negative impact was demonstrated repeatedly (Heller and Arnold, 2010). In a study comparing siblings of children with autism as well as intellectual disability, with siblings of those with *only* an intellectual disability, the first group were reported to have more emotional difficulties (Petalas et al, 2009).

7. **Presence of challenging behaviours in the child with a disability** exerts a strong negative influence on their siblings. Hastings (2007) found that there is a significant correlation between

behaviour problems in the child with a disability and level of behavioural difficulties in the typically developing sibling, while Orsmond, Kuo and Seltzer (2009) found that challenging behaviours result in siblings being less willing to be involved in joint activities, particularly when in public. In an Australian study involving twenty-five siblings of children with an autism spectrum disorder, 84% of the siblings cited aggression exhibited by their sibling with a disability as being a significant problem (Ross and Cuskelly, 2006).

8. **Well-being of the parents** – the necessity of devoting large amounts of time and attention to the child with a disability can have a negative effect on that child's siblings (Bachraz & Grace, 2009). High stress levels in the parents lead to higher stress levels in the typically developing child (Giallo & Gavidia-Payne, 2006). Depression in the mother, in particular, has a detrimental effect on siblings (Meyer et al, 2011). The AIFS report that when a parent who is also a carer suffers from depression, the typically developing siblings are around four times more likely to experience a depressive episode than under normal circumstances (Edwards et al, 2008).

5.1.1 Sibling Studies

Research involving the siblings themselves has resulted in both positive and negative attitudes being described. Heller & Arnold (2010), in their review of research into siblings of adults with developmental disabilities, reported that "*the majority of studies found that siblings had positive relationships with their brother or sister with disabilities*". One of the studies they examined, conducted in the US with 460 siblings of people with either Down syndrome or autism, found generally positive attitudes (Hodapp & Urbano, 2007).

Australian researchers Bachraz & Grace (2009) found that siblings did not consider their brother or sister with a disability to be a burden, but rather accepted them as distinctive and special. A sense of empathy

in the siblings has also been noted (Benderix & Sivberg, 2007), whilst Macks & Reeve (2007) found siblings of autistic children rated themselves more highly for behaviour and performance at school than the siblings of children without disabilities.

In this ANGLICARE study there were some positive sibling relationships described, in spite of the behavioural and communication difficulties present. For example, Ruby stated that she and her sister Belinda like to "*chill out and relax*" together, while Matthew described the long walks he shared with his sister as being a positive and happy experience.

A degree of ambivalence was noted in some cases, especially where the severity of the intellectual disability and/or the high level of care required can form barriers between siblings:

> I mean she'll look after him for the basics. She won't change his nappy but that's a different story. But you know she'll feed him and give him drinks and stuff, whatever. She's not particularly endeared to him … she's not particularly loving to him, but she's alright. (Kathryn, mother)

Siblings in other studies have reported a variety of negative emotions felt towards their brothers or sisters with a disability. Some of these emotions include anxiety, embarrassment, bitterness and fear (Benderix & Sivberg, 2007); guilt and shame (Caplan, 2011; Abrams, 2009); deep hurt (Abrams, 2009); loneliness (Meadan, Stoner & Angell, 2010) and anger (Ross & Cuskelly, 2006). These last authors also reported that siblings spend much time indulging in 'wishful thinking', that is, dreaming of a life without the family member with a disability.

The fifty siblings who participated in the recent study by Moyson & Roeyers (2012) made remarks such as "*I really wish I had a normal brother or sister to do all the things together*" and "*I can't do … things with my sister and then I feel sad*". The siblings interviewed by Mascha & Boucher (2006) cited aggression and bad temper as their biggest frustrations; the research by

Ross & Cuskelly (2006) found that 84% of siblings named aggressive behaviour as their biggest source of stress. Benderix & Sivberg (2007) found that the siblings were frightened by the challenging behaviours, especially when the child with a disability is violent towards them or other family members.

Lower levels of performance at school have been recorded, along with reduced levels of participation in extra-curricular activities (Barak-Levy, Goldstein & Weinstock, 2010). Social life, that is, just spending time with others in both formal and informal settings, is curtailed for siblings (Barak-Levy, Goldstein and Weinstock, 2010; Benderix & Sivberg, 2007). One possible explanation for this curtailment is the unpredictable behavioural patterns of some children with intellectual disabilities and the ensuing embarrassment on the part of the sibling; for example, some siblings do not want these children and their problem behaviours seen by their school friends (Mascha and Boucher, 2006). Even being observed in the company of a sibling with a disability can cause discomfort: as a participant in one study commented: "*If we go out for a walk with her, then people are really staring at her and at us!*" (Moyson & Roeyers, 2012: 97).

Psychotherapist Roberta Caplan (2011), reporting on her clinical experience with US college students, found that siblings of people with a disability have difficulties in relating to their peers while at college, especially those who exhibit any form of behavioural problems such as a bad temper. Siblings can feel an over-developed sense of responsibility for the actions of other students as a result of assuming responsibilities at home that their peers have never experienced.

Finally, the siblings themselves may exhibit problem behaviours of varying kinds: an almost two-fold increase in the likelihood of hyperactivity or inattentiveness was found among healthy siblings of chronically sick children, when compared with their peers (Besier et al, 2010). This has been demonstrated to relate to the level of problem behaviours exhibited

by the developmentally delayed child (Hastings, 2007).

5.1.2 ANGLICARE Findings

The siblings in this study grew up being subjected to, and witnessing, challenging behaviours which were sometimes violent. Parents reported that siblings were sometimes intimidated and siblings themselves reported that they had experienced some form of aggression:

> *… but Shane as he got older would just physically intimidate Hugh out of the room. (Elizabeth, mother)*
>
> *So he would sort of, kind of come at me and he would often try and hit and pull hair. (Hugh, brother)*
>
> *Basically I can't let him go upstairs when the other two are up there doing homework or on the computer because he'll try and drag them somewhere. (Sally, mother)*

Acts of aggression were sometimes targeted at younger siblings who were smaller physically and less able to defend themselves:

> *…it was my youngest daughter that had the worst from him… Simon can see she is still smaller than him so I always tell her "Don't go near to Simon, don't go near", that's all I can tell her because he will grab her. (Letitia, mother)*
>
> *He'd pull her hair, he'd scrunch her and she didn't have the physical size or strength to overcome that… (Margaret, mother)*

For others, who have left the family home, their own children have on occasion been at risk:

> *… my daughter took her daughter to the airport to pick us up and Simon just lashed out …and he*

freaked my eldest daughter because she's got a baby in the pram. (Letitia, mother)

As a result of these behaviour patterns, the lives of the siblings were altered both within and outside of the home environment. At home, they were subject to highly unusual restrictions which involved locking their rooms to ensure safety either of themselves or their belongings:

… she spent the first six years of her life, when Peter was at home, she would sit on the top step to watch television because she just knew that Peter would … hurt her. (Margaret, mother)

Simon will go to their room and he just messes up the whole room after they've tidied the room up. Yeah, because they come out … sometimes they forget to lock their room. (Letitia, mother)

… we've always said even to Marcia too that you know you can have friends over, but they just have to accept Andrew the way he is, you know. And if they're not going to accept him, we don't want them coming over. (Kathryn, mother)

So it was quite um, difficult having friends over and well we didn't really. (Rachel, sister)

"He'd pull her hair, he'd scrunch her and she didn't have the physical size or strength to overcome that."

As a result of the combination of these factors, several parents stated that the stress on their other children was so great that it resulted in psychological and emotional health issues:

… she's [her daughter] actually suffering from stress herself. (Sarah, mother)

But he didn't want to worry us about anything so he just shouldered everything himself and just kept it on board … in … you know and he had a complete breakdown. (Elizabeth, mother)

Siblings reported a range of emotions in this study:

- **Embarrasment:** Parents reported embarrassment at siblings having to try to justify certain behaviours of their brother or sister. One sibling expressed both embarrassment and frustration in trying to explain her brother to others:

…poor Zac, you know, the look on his face was just horror of, like, if anyone ever found out that my brother did that … (Amelia, mother)

…I remember in primary school someone asked me what's wrong with him. It was just their way of enquiring, but it just sounds so horrible, you know. "What's wrong with him?", "Nothing's wrong with him!", he has a disability but yeah, it's just too hard, it's the too hard basket. (Rachel, sister)

- **Resentment:** There was resentment at the amount of attention that the child or young person with a disability requires and at the same time the sense of frustration when games or activities were destroyed:

They get frustrated with him if he's grabbing them. My younger son tends to not punch him hard … There was a bit of angst for a while with Tim saying "Joel gets all the attention!" because when he is here he does get all of our attention or a lot of our attention. (Sally, mother)

…the frustration I think, I suppose was, look, I get that he wouldn't even, you know, he wouldn't necessarily be able to build them with me but, like, at least it would be nice if he didn't destroy them with quite as much. Because, you know, I did put in a lot of effort into these, you know extensive and elaborate Lego objects. (Hugh, brother)

- **Anxiety:** Others talked about how their adult children were anxious for their parents after they had left home:

… they always ask "How is Simon?" so I tell them "Oh, he's fine, oh, no, we're having a big problem with him". So they say "Mum be careful with him… yeah, well be careful, don't take him to the shopping centre if he is not good mum". (Letitia, mother)

- **Fear:** Fear, especially as a result of aggressive behaviours, was expressed by one of the three siblings interviewed. A mother also revealed how fear for her own safety had meant her other children felt the need to come to her defence:

You know and it looks like he's going to attack me but he's really just getting me so close to him. The hard part with that is for the boys, it's very hard for them to see that happening and on this particular occasion, you know, Jacob grabbed the cricket bat, "I'll get him mum!"… then that of course escalates everything worse. Zac is trying to pull him off me and then Michael is in the way ….sort of pull their hair and that's really, really heartbreaking for me to see 'cause it's their brother and they don't understand, I'm their mum, they don't understand why is he attacking me and that's when they want him to go. (Amelia, mother)

… all of the fear was kind of internal …. just because of the way that things can go in other circumstances. (Hugh, brother)

- **Loneliness:** Siblings and parents also talked of the loneliness experienced because the siblings could not bring friends home nor did they feel as if they could explain the situation to anyone outside the home:

You can end up quite isolated because the, ah, you don't have time to see people or they don't really understand or um, they get a bit put off and not really sure what to do and, some people just drift. (Rachel, sister)

…there was only one friend that knew about Jordan. She didn't disclose to her other friends. She had other friends at school and in high school. There was only one that knew and I didn't realise that until quite later in time. (Eileen, mother)

As a result of their unusual family environment, the siblings of children with an intellectual disability have a tendency to mature quickly (out of necessity) and have learned at an early age to deal with their own problems rather than place any additional strain on their already over-burdened parents (Bank & Kahn, 1982, cited in Abrams, 2009).

Rachel reported that she "*could have gone to my parents if I needed to*" but that instead, she "*just grew up quickly and looked after myself rather than burdening them*". In her case, she described a felt need to be successful in her life in order to, in some measure, compensate her parents for having a child with a disability. Others described similar emotions:

I think the fact that I was isolated and the fact that I was a competitive kid as well and wanted to prove myself meant that yeah, I think that I threw myself into my studies. (Hugh, brother)

A couple of [friends] have said that the reason why you're going so hard, you just can't stop, you have to succeed to show your parents that all the hardships they went through is worth it. I love seeing my mum and dad smile when they hear I've challenged some of the conquests. (Matthew, brother)

These remarks are consistent with other studies in the literature where siblings have reported that they rate themselves more highly than their peers in terms of life achievements (Macks & Reeve, 2007).

Sometimes, siblings develop great empathy, which is initially directed towards their family member with a disability:

Sandra had been on the computer and she had typed a thing about watching Lucy having this

seizure and how it upset her and I just sort of picked this thing up and just started reading it; what she'd typed. So it was a little bit of an insight. (Janice, mother)

For others, the experience of having grown up alongside a sibling with an intellectual disability may lead to a desire to work in some form of caring role, or allow them to have an attitude of understanding (which they may not otherwise have had) towards others they encounter later in life:

If I think about my life and how much I've got going for me and how few problems I have but relatively speaking, you know, you still get frustrated, you still have little things that nag at you … just compared to the difficulty and the huge project of dealing with a child with a severe intellectual disability it's just, I'm just kind of blown away. (Hugh, brother)

He really loves Michael and has a real compassion for him. He often says "I'm going to be a carer, mum, when I grow up" and he's got that kind of personality. (Amelia, mother)

It definitely has played a huge part … my sister taught me to care unconditionally. (Matthew, brother)

The siblings expressed admiration and respect for what their parents had been through:

Every time I think about it and talk about it I've got more respect for what my folks were able to accomplish because I feel like I was able to perform to my full potential in all the fields that I wanted to. (Hugh, brother)

Accompanying the feeling of respect for their parents was a feeling of disappointment that those outside the family were unable to comprehend the nature of the situation:

I was … always quite cross at other people for not understanding my situation or the family. (Matthew, brother)

Compassion and understanding are traits which these siblings look for in others. Ross remarked about his two children:

… both of them have said that when they are assessing other people that they come in contact with … one of the things that's high on the criteria list is how that person interacts with Jordan and how they accept Jordan.

For Hugh, a desire for a compassionate life partner meant he set himself a mental rule:

I wouldn't really worry about bringing a girl home until like I'd told my story to them and get them psychologically ready to meet Shane anyway.

Given that, as he later went on to describe, his wife has been subjected to aggression from her brother-in-law ("*[she] has copped a few hits and a few hair pulls*"), the need to 'screen' potential partners in order to assess their ability to cope with someone with challenging behaviours is great, but once again, means that the siblings face additional hurdles in life which are outside the experience of their peers.

5.1.3 Support for Siblings

Siblings themselves desire information, both about the nature of the diagnosis of their brother or sister with a disability but also about the support they can expect to access (Davys, Mitchell and Haigh, 2011; Abrams, 2009). Organisations such as Siblings Australia exist with the purpose of providing information and support for these siblings. Peer support can also be important. The siblings interviewed in this research related positive experiences from contact with others in similar situations:

So I was with my care group and they were caring siblings obviously and we would all care for our

siblings together ... and just wanted an excuse to go on a holiday together and just relax without any scrutiny. (Matthew, brother)

Yeah, as I said, sitting in a room full of people who actually got it... who understood.... you didn't have to explain it. (Rachel, sister)

Regular, high-quality respite care provides the opportunity for social activities both within and outside of the family home. Residential accommodation options, such as the Kingsdene School, also provided much-needed relief for this particular group of siblings. Having their sibling with a disability away from the family home for periods of time was viewed in a positive light by those interviewed by Benderix & Sivberg (2007). Some 93% of the siblings surveyed in a recent UK study stated that even a short break, such as respite care, enabled them to have more, and better quality, time to spend with their parents and other children (Welch et al, 2012).

5.2 FAMILIAL AND BROADER SOCIAL RELATIONSHIPS

Family relationship problems, if present, have a negative impact on parental psychological health. Where carers report one dysfunctional relationship within their family, the incidence of depression among carers is four times higher than for those reporting no dysfunctional relationships. A higher number of dysfunctional relationships within the same family further increase parental stress levels (Edwards et al, 2008). These findings are supported by other studies in Australia as well as the UK and the USA (Khanna et al, 2011; Edwards & Higgins, 2009; Emerson, 2003).

5.2.1 Family Unit Activities

Caring for a child or a young person with a disability who also has challenging behaviours can seriously impact the number and nature of family activities that can be enjoyed. Only 'safe' destinations can be

visited, especially when only one parent is going on the outing:

We just go for a drive. And stop at the fast food takeaway McDonalds and pick up some food … and then we just go to the park or to the nursery. At places that is safe for him and easy for me if the situation arises. (Letitia, mother)

Margaret described an embarrassing situation which arose during a simple trip to the supermarket with her children:

[Her daughter] would be walking along holding his hand and she'd say, up on the main street just outside Woolworths and she'd say, "Mum his pants have fallen down". She grew up with that and I sort of looked down and "Oh God his pants have fallen down and he's got his hand in his nappy".

Noeline explained that the only place she was able to take her daughter Belinda was to the local Westfield shopping centre food court. Here, Noeline would sit for several hours while her daughter would walk around the outside edge of the central eating area and no one could persuade her to stop until she herself determined that the activity should come to an end.

Small outings require planning and forethought. Longer excursions such as family holidays could be problematic. Rachel described holidays, for her parents, as simply "looking after Jordan somewhere else". Similarly, Tammy explained that:

… at present the challenges are probably, you know, trying to get away, holiday, and that's not happening.

For many parents, the variety of care needs, medications and equipment required, and behavioural issues including the need for locks on cupboards and the refrigerator, had made holidays not really possible. Parents with access to respite care services were able to have occasional short breaks

outside of the family home. Unfortunately, due to the volatile nature of some of the children, either behaviourally or medically (e.g. frequent seizures), these excursions were reported as often being cut short. Even having respite did not achieve its goal of reducing stress because the parents were constantly waiting for a phone call to interrupt their time out and summon them home:

So no, you don't completely relax. But you've always got your phone with you and if it goes off your heart stops momentarily. (Mark and Christine, parents)

You know we don't often go out for lunch but two occasions we went out with the same couple … and they called us up, we had to quickly finish our lunch, I said "so sorry we have to go" and it was so embarrassing. (Letitia, mother)

For Phillip, a short break at the movies is not an opportunity for recreation, but rather, to catch up on some desperately needed sleep:

I slept from the beginning to the end. So exhausted you know. So that's why I slept and at the end my wife said "Phillip, Phillip, wake up, wake up". I said "Why?" "The movie's ended, we're going home".

The combined effects of the lack of suitable environments outside of the family home to which families can take their child with a disability, along with the restricted ability to have social interaction while the child is cared for by someone else, mean that these parents become isolated and disconnected from their communities. Such connections are important. Studies have demonstrated positive associations between the availability of social support networks and levels of well-being amongst parents of adolescents with severe intellectual disabilities (White & Hastings, 2004, p 187).

Some parents in ANGLICARE's study described their situation as follows:

… you're not integrated into society. You're isolated with his society. (Ross, father)

We don't have great aspirations in a social life and in fact what we've been through really knocks the confidence out of you. (Eileen, mother)

5.2.2 Support from Extended Family and Friends

The availability of informal support from other family members and friends also has a bearing on carer mental health; carers who have no such support have mental health levels which are significantly lower than carers who receive support (Edwards & Higgins, 2009). The parents of children with an intellectual disability report that their friends are unable, for whatever reason, to deal with the presence of the child with a disability and thus withdraw from the parents, leaving them feeling isolated and lonely (Myers et al, 2009).

Acceptance of the child with a disability by friends and neighbours is certainly not helped by the presence of challenging behaviours. In a survey of caregivers of children with autism spectrum disorders in rural Victoria, it was found that 22% of the respondents felt that there is a lack of understanding in the general community of behaviour exhibited by these children, and 95% reported being concerned about the child's behaviour when out in public places (Higgins, Bailey & Pearce, 2005, pp 131-132).

Family members in the ANGLICARE study described their lives as being characterised by loneliness and isolation. Very few had the privilege of having extended family living close by when their children were born or in the early years of their children's lives. Many were forced to deal with their difficulties of adjusting to life with a child with an intellectual disability and challenging behaviours without the support provided by relatives.

Elizabeth spoke about the embarrassment her son caused to her mother who, because of her cultural

background, viewed those with an intellectual disability as "*disgraced by God*".

For Amelia, the disability suffered by her son Michael resulted in his being all but ignored by her relatives, for example, "*no birthday cards, no nothing*". This denial of Michael's existence had affected most members of her extended family:

> *I just think they're uncomfortable with Michael so again, you know, you find that you don't get invited to the cousin's birthdays, you don't get to do the sort of the normal things that I would imagine sisters with kids should do. You know, yeah, just I feel very hurt that they don't treat Michael as a normal grandson or cousin.*

Similarly, Letitia commented that relatives may have kind words, but these are not translated into practical action:

> *I don't get support from any relatives … they may sound very compassionate and understanding but …*

For Kathryn, however, the situation was different. The home of a close relative is the only other home she feels comfortably able to visit with her son:

> *Well the only place we would take him is if we go to mum's because her house is reasonably friendly or we can sort of put things away. He knows the place instantly like he'll walk in. He knows exactly where he wants to go and what he'll play with. But I don't know of anyone else of our peers or our friends who've got a house that you would take Andrew to where we wouldn't have to be watching him, holding him, restricting him the entire time which defeats the whole purpose of going there.*

While Kathryn is able to spend time with extended family, this is the full extent of her social sphere; the behaviour of her son precludes socialising in the home of anyone else.

Regular family celebrations such as birthdays and weddings require additional planning and forethought as a result of both the care needs and behavioural issues of the young person with a disability. Often, a carer (or multiple carers) has to be hired for the day so that family members may focus their attention on the event instead of on their child with a disability. For example, Daniel and Janice described needing to hire a carer to look after Lucy at the weddings of two of their other children. This situation, however, only allowed them limited freedom. One of them was required to drive Lucy and the carer back to the hotel room between the ceremony and the reception, since legal requirements prevented the carer from being allowed to drive. In Phillip's case, he and his wife, even with the assistance of a carer, had to take turns at their daughters' weddings: one attended the ceremony while the other attended the reception.

Family members described their lives as being characterised by loneliness and isolation.

Elizabeth explained that she really wished that her family had made more effort to understand her situation, and now, when asked to give advice to young parents going through what she endured, advises them as follows:

> *Make your family see; tell them you need their help. And then they say "Well what about if they don't want to help?" at least you'll know and they'll know. At least you'll know and you will have to forgive them because they mightn't be able to cope but at least you'll know and they'll know what you go through. You know that's one of the things that I really felt like I failed to do that because I didn't want people to see how bad it was for me.*

Friends, in the experience of those interviewed, have displayed similar reactions. The child with a disability, especially when given to episodes of

challenging behaviour, causes discomfort and/or distress, and friends feel unable to cope, so they resort to withdrawal:

… you know it [the intellectual disability] does make people feel uncomfortable. (Amelia, mother)

…those formative years a lot of our friends couldn't come around either 'cause Shane would attack the children and hit the children. So for probably about five or six years we were very, very lonely. (Elizabeth, mother)

…'cause when you have a child with a disability who's disruptive and aggressive and all those things, your friends just drop by the wayside. You just don't have friends anymore. (Evelyn, mother)

The company of other parents who have children with a disability, and therefore who understand the situation, can provide some support:

… most of my friends were people who had autistic kids. (Amelia, mother)

Really more the three mums. The three of us, we try and meet. We live in very different areas, because no one else understands, no one else … So they understand those things, or we often text each other on a Saturday morning to see who's had to get up the earliest, which no one else would understand. (Sally, mother)

Others mourned the loss of close friendships over the years and could see their friends as they age now having fewer responsibilities as their children left home:

…it's like you've missed ten years, for me probably ten years, you know, of my life where you could have normal friendships. (Amelia, mother)

So now that most of our friends are empty nesters …that's when it's hurting. (Tammy, mother).

6. CARE AND SUPPORT NEEDS

During the course of the interviews it became apparent that there were a number of service areas that were critical to these families – including greater access to respite care, support with dental and medical visits and lack of service support to the point where parents feel forced to relinquish their child. Each of these issues will be discussed in turn in the following section.

6.1 RESPITE CARE

The amount and level of respite required is dependent on a number of factors:

1. **The presence of challenging behaviours** was the most commonly cited reason in the literature for families seeking respite from caring for their child or young person with a disability (Chadwick et al, 2002). Nankervis, Rosewarne and Vassos (2011) examined the case files of thirty-two intellectually disabled people and found that the constant vigilance required when there is a child with challenging behaviours in the family is a major factor in the decision to seek respite placement. These authors also noted that parents expressed concern about the increasing difficulty in managing these behaviours as the child grows physically.

2. **The level of intellectual disability present in the child** is another important factor. Children with more severe disability levels are more likely to cause their parents to seek placement (Chadwick et al, 2002).

3. **Complex needs** present difficulties; many of these children requiring 24-hour care, which proves overwhelming for many parents (Hostyn and Maes, 2007; Mc Gill, Tennyson and Cooper, 2006).

4. **The general well-being of the parents** - Parents interviewed by Chadwick et al (2002) reported that their high levels of stress led them to seek respite care for their children. Poor mental and physical health was also demonstrated to be problematic for Australian parents who placed their children into respite care (Nankervis, Rosewarne and Vassos, 2011).

5. **Concern for the well-being of siblings** - has also been cited as a reason to seek respite care. Even short breaks have been demonstrated to have positive effects on the well-being of the other children in the family. In their international literature review, Robertson et al (2011) found that these breaks allowed parents to engage in activities with their other children which would not be possible if the child with a disability were present. In addition, the mere fact of being able to spend extra time with the other children, giving undivided attention, was shown to be of great benefit to both parents and children.

Whether physical or mental stress, or a combination, is the problem for individual parents, research has shown the benefits of having respite care available. A recent study in the UK found that regular access to respite care reduces parental stress levels (Welch et al, 2012), a finding which has been supported in an international literature review (Robertson et al, 2011). As to the specific means by which respite care reduces parental stress levels, parents have stated that respite care allows them to catch up on important activities ranging from sleep to socialising (Robertson et al, 2011), and to devote more time to other areas which have been neglected, such as other family members and their own careers (Hostyn and Maes, 2007).

The benefit to siblings ranged from spending quality time with their parents, to having friends over and

helping to form new friendships (Welch et al, 2011). Of the parents interviewed by Alborz (2003), 78% said that their primary reason for seeking alternative residential care was concern for the state of their family life. This has been reflected in many other studies conducted internationally; short breaks allow families to have improved quality of life and to have 'a more ordinary life' (Robertson et al, 2011). Australian parents, when interviewed, stated that the difficulties their families faced in dealing with the needs of all family members was an important factor leading to their decision to seek alternative care (Llewellyn et al, 2005).

"Quite often we'd get calls and he had to be brought home from respite 'cause he was acting out."

The reality for the families in the ANGLICARE study is that, while respite services have the potential to provide relief, parents felt they were inadequate for a number of reasons. Some felt that the service was too infrequent, perhaps once every three months. Others felt that the respite providers required requests to be made well in advance which did not take into account crisis issues and unscheduled or spontaneous family events:

> *We need to give family carers more respite, you get to the point where respite is not enough because you've gone too far. (Evelyn)*

> *… had to decide whether to request specific dates for respite so I could have a birthday party or we could go on holiday or just a busy time whatever, um, or just say we don't mind when and increase your chances of getting respite, 'cause you had more chance of getting respite if you didn't specify when. (Rachel)*

Additionally, there was the issue of dealing with multiple service providers and lack of appropriate

coordination so that offers of respite might well clash for the same weekend:

> *I missed out the last three months because they gave a double up and I just got the letter two days ago. You get one weekend in three months and they give you the same weekend as you got from [another agency]. So it's frustrating to say the least. (Kathryn)*

Parents alluded to the fact that they would often be called mid-way through the respite to come and take their child home – either because of some physical issue or because of their challenging behaviour. Indeed exclusion from respite services because of challenging behaviours has been reported in other studies (Llewellyn et al, 2003, Wodehouse and McGill, 2009).

One parent in this study felt that the young person with a disability realised that if his behaviour was challenging then he would be taken home. This in turn meant that parents could never be assured they would be able to enjoy the whole break:

> *…within half an hour they ring [and] say "Come and pick her up", because she vomited. "Our policy is when they vomit they go home". It was …distressing too … we were just about to go somewhere else you know, no contact, phone contact of available, it was not easy. (Tammy)*

> *… quite often we'd get calls and he had to be brought home from respite 'cause he was acting out. And that became a big worry and so, there was a time when respite was, you know, there was always questions around whether he'd be able to stay and so it wasn't really, it became quite stressful as to you know there wasn't enough and they were having problems at respite because Shane was sort of starting to realise that if he was, if he acted out he would kind of get taken home.(Hugh)*

The short duration of respite care also meant that the respite services never really got to know the young person with a disability well. This meant that the

support staff were not always aware of the issues, how the young person needed to be treated and that the young person often felt uncomfortable or even frightened of the new environment.

Sometimes they don't even realise she's been hurt.. and this was a Sunday evening when then we had to go get her x-ray done and she just … so two days in respite and four days at home with something like that. So respite backfires. (Tammy)

6.2 SUPPORT WITH MEDICAL AND DENTAL VISITS

A recurrent theme throughout the interviews was the particular difficulties which have arisen when children with an intellectual disability require attention for regular medical and dental issues. The problems encountered have stemmed from a number of sources:

1. **The children have significant communication deficits,** so are unable to communicate if and when they are in pain, or assist in any way in the diagnostic process.

2. **The children have difficulty comprehending** the need for physical examinations and treatments, or that the medical professionals are seeking to help and not hurt them.

3. **The presence of any of the challenging behaviours** described earlier in this report means that the assessment and treatment processes become longer and more complex. As found in previous research, the presence of pain or discomfort has the potential to exacerbate existing challenging behaviours (De Winter et al, 2011). Medical personnel are sometimes unable to distinguish between behavioural problems which arise from the young person being in pain, and those which accompany their disability:

I think somewhere in one of the hospitals they assumed that the behaviour of the patient was related to their disability …but it wasn't. Yeah. And there were some issues. So that's why it's saying that-don't just assume that whatever …their behaviour is, is part of their disability. (Tammy, mother)

4. **Waiting times are an issue** – these children and young people are in a new environment which is sometimes intimidating and they do not have the social skills to sit and wait their turn. There is also of course, the issue with other people in the waiting room, who do not understand the nature of the disability and the challenging behaviours which may be associated with it:

It's just the wait: she can't wait. You know, socially, she doesn't have the social skills. You know, people look at her, stare at her. (Janice, mother)

I mean he can't wait in waiting rooms even if you make an appointment. If the doctor's not on time then it's, you'd have to walk go out and walk around for ten minutes come back check where they're up to. (Rachel, sister).

5. **Many of these young people require sedation or a general anaesthetic** to be administered in order for basic examination and treatment processes to be carried out, which is both time-consuming to organise, and adds considerably to the overall cost of each procedure:

I found a 'special needs' dentist that we've been going to for a few years. That hasn't been too bad; any dental work he has done under a general anaesthetic. (Sally, mother)

Well it took seven of them to actually pin him down and so that the ambulance paramedic … can actually give him a needle. Not in a vein just a needle somewhere to …paralyse him a little bit until he can … so that they can put him in the ambulance and take him to the hospital. (Sarah, mother)

6. **Lack of knowledge by medical personnel about the particular disabilities and challenging**

behaviours of the patient - Within the literature, it has been observed that general medical personnel display a lack of knowledge about the particular needs of intellectually disabled patients (Wodehouse & McGill, 2009; Torr et al, 2008). This lack of knowledge has been found by the families in this study to manifest in a number of ways including some insensitive comments by staff, unwillingness to listen to the parents who generally understand and know the young person well and proceeding with a treatment regime which the parent knows will not work for the young person.

I have never forgiven the Paediatrician who told me abruptly that "she's got a problem". It wasn't done with empathy, it wasn't … it wasn't with the caring and maybe at that point he should've said "Maybe you could talk to the social worker … we'll get you in somewhere", you know. But no. (Tammy, mother)

And they're [doctors] frustrating too because basically they don't sort of take any notice of you. (Mark, father)

And I'm trying to explain to the doctor "But you can't stitch him up 'cos he'll rip it out". (Rachel, sister)

As a result, attending to basic health care needs may become so difficult that it is simply a task which is ignored:

So dentistry, yes, and we are overdue now but the thought of it just gives you the creeps so you just don't do it. (Christine, mother)

6.3 BREAKING POINT AND RELINQUISHMENT

In May 2012, the Victorian Government released a report into the relinquishment of children with a disability into State Care, entitled *Desperate Measures,* which stated that "*without adequate support, some families reach crisis point*" (Victorian Equal Opportunity and Equal Rights Commission, 2012:6). No such review has been conducted in New South Wales, but all of the participants in the ANGLICARE study outlined the current situation in this State: that full-time supported accommodation is only provided if families resort to relinquishment which, in practical terms, means taking the young person to respite care and not returning to reclaim them. This painful process has been the experience of three families participating in this project. Other participants, while not having reached the point of relinquishment, expressed frustration at the knowledge that, currently, it is the only guaranteed method of obtaining full-time accommodation.

For those who had reached crisis point, the emotional strain involved in relinquishment was enormous:

People were surprised we lasted as long as we did. I think it's two years before it got to the point where my parents couldn't cope anymore. (Rachel, sister)

I'm sorry to say that but that was the only choice we had because it was so difficult for us. (Letitia, mother)

… it just came to me. I just can't keep doing this and we're just going under and I thought this is it. There's no way out. (Eileen, mother)

In addition to the turmoil involved in giving up a family member, participants described the guilt they felt towards other families in the same situation; they knew that their child was now occupying a respite care bed for longer than usual, thus denying other families access to respite care and increasing their burden of stress:

There's that guilt of queue jumping as well. (Rachel, sister)

The only way to achieve this was by irregular means which was leaving him at respite and denying other, well deserving families that respite space and

knowing how much those other families are hurt by not having enough respite. (Ross, father)

Once they have recovered from the anguish of abandonment and feelings of guilt towards other families, participants spoke of the benefits to themselves and other family members which they have been able to enjoy due to the separation of the young person with an intellectual disability from the family home:

… it's been good for him and good for us. (Letitia, mother)

… we can live a normal life now. (Ross, father)

The frustration of being forced to deal with a system which requires relinquishment as a last resort was evident among participants:

We don't have a choice, you either relinquish your child …or this is what you do and that shouldn't be a choice because, you know, we talk about human

rights all the time, what about the human rights of the parent?" (Evelyn, mother)

I was desperate for some help and I think I rang [them] … to say like "I can't do it anymore", crying my eyes out and this awful, awful woman basically said to me "Well what do you think we've been waiting for you to do for the last two years". (Amelia, mother)

But we shouldn't have been forced to such extreme measures and in such an extreme situation...they knew about us and we got a lot of sympathy and a lot of words of encouragement but no actual help. (Ross, father)

Relinquishment is a desperate measure which parents only undertake, in this study, after they have reached breaking point. What policy measures are required in order to mitigate some of the impacts of caring with a child or young person with a disability and challenging behaviour? The next chapter explores these issues and offers some recommendations.

7. WHAT CAN BE DONE?

Apart from the experience of raising a child with an intellectual disability, a common thread which unites these families in the study is the experience of the shared care arrangement provided through the Kingsdene School program. For these families such a program provided educational opportunities around the development of life skills and mid-week respite to enable better family functioning, parental well being, and opportunities for employment and support for siblings.

The closure of the Kingsdene program has meant that these families now rely upon other kinds of support in raising their child. What kinds of supports are available to them and how do they compare with the Kingsdene approach? In addition, Australia is on the verge of the introduction of the National Disability Insurance Scheme. This chapter considers the benefits of shared care and residential placement as part of a suite of approaches that would be possible under an NDIS.

7.1 TRENDS IN RESIDENTIAL PLACEMENT

Current policy favours the retention of children and young people with an intellectual disability within the family home. This policy has seen a move away from support for long-term residential care facilities. In the 1960's parents with a child who had an intellectual disability could choose to place their child in a purpose-built institution and there the child would live for the rest of their life. Australia like other Western nations began to close such institutions from the 1970's onwards (Mansell, 2006). Some of these institutions had achieved public notoriety, with a reputation for being at best, unsanitary and at worst, degrading and neglectful. St Nicholas' Hospital in Carlton, Victoria, was one of the more notorious examples, and was finally emptied of its 102 residents in 1985 (Cummins & Dunt, 1988). In 1998 the New South Wales government pledged that all large residential facilities in the State would be closed by 2010 (NSW Ombudsman, 2010).

Consequently, the alternative residential options available for families with children and young people with an intellectual disability are small group homes and respite care facilities. Other countries have facilities not available in Australia: for example, the United Kingdom has both purpose-built facilities which house 20-25 residents (Knapp et al, 2005), and residential schools (McGill, Tennyson and Cooper, 2006). Kingsdene School, with a mid-week residential component, was a unique facility in New South Wales. With its closure, the only option for residential schooling for children with an intellectual disability in New South Wales has been removed.

Over the last three years with the emergence of the National Disability Insurance Scheme (NDIS) there is now a strong imperative for the inclusion of children and young people with a disability in mainstream services. At the opening address of the Federal Government's Social Inclusion Conference (January, 2010), the Hon. Jenny Macklin, Minister for Disability Affairs,[6] commented:

> [It has been] cruel and punishing, with a terrible physical and emotional legacy endured by people ... when left [in] institutions. [We need to] build the social infrastructure that underpins social inclusion [for Australians with a disability].

At the same time, policies in relation to children and minors is predicated on a belief that the best place to live for children and young people with a disability is the family home.

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6.   The Hon Jenny Macklin was also the Minister for Families, Community Services and Indigenous Affairs.

7.2 OUT-OF-HOME CARE

Government policy in relation to out-of-home-care (OOHC) of children within Australia has swung along the pendulum from child removal to family restoration. Within contemporary Australia, in most jurisdictions, the underlying priority has been to keep children within their original family unit wherever possible. However, Australia has experienced an increase in the number of children entering out-of-home care, and many of these children are presenting with increasingly complex and challenging behaviours. At the same time, there has been a rapid decline in the number and prevalence of suitable residential placements for young people with a disability, without a concurrent increase in alternative placement options (Smyth & Eardley, 2008).

The reduction in placement options has been linked to many factors, including:

1. A decline in the provision of residential care for children in the last four decades[7];

2. Recognition of problems caused by institutionalisation; and

3. Revelations of the experiences of the forced migration of children from Britain and Ireland in the earlier years of the last century.

Residential care for children has also declined internationally as a result of research on child development, particularly in light of theories of 'attachment', highlighting the detrimental effects of institutionalisation. The focus on de-institutionalisation, normalisation and 'least restrictive environment' has been compatible with government efforts to reduce welfare spending, leading to the closure of relatively costly residential placements. A few residential placements are still

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7.   Although the decline in residential care for children is consistent with international trends (cf the US and UK), Australia has observed a much sharper deterioration than in either the US or UK (Smyth & Eardley, 2008).

provided for children with severe emotional and behavioural problems. Over the last few years, there has been some growth in privately run, for-profit residential provision for children in out-of-home care. These services tend to be costly and only loosely regulated, often employing untrained staff (Smyth & Eardley, 2008).

7.3 RESIDENTIAL SCHOOLS

Reviews of residential special schools in the United Kingdom have revealed benefits for both the students and their families. As articulated by parents, the inherent benefits of the residential facility included:

- social aspects, in particular, the opportunities to socialise with friends and with students with similar disabilities

- increased independence

- improved confidence

- specialised staff, environments and equipment

- continuity of education

- access to a wide range of recreational activities on afternoons and weekends

- satisfaction with much needed respite

- being able to give more attention to the broader family unit and in particular, typically developing children. (Hallett, Hallett & McAteer, 2007; McGill, Tennyson and Cooper, 2006).

High quality care and socialising were prioritised by both parents and students alike, over curriculum driven programs. As Morris, Abbott and Ward (2002:71) have reported, educational professionals cite 'social reasons' as the key drivers behind parental decisions for enrolment into residential schooling. In addition, parents have repeatedly articulated their difficulties managing and coping with the needs

and behaviours of their children, particularly in the absence of supportive social services. Roberts and Ridley (2009) note the benefits of residential special school settings, particularly for the promotion of socialising, student independence and self-esteem.

Parents reported a significant reduction of stress and despair once their child was settled at Kingsdene.

The participants in ANGLICARE's study reflected on the benefits of having access to the Kingsdene Special School and its residential facility:

1. The school imparted **significant life skills** such as independent feeding and dressing.

2. **Sleep patterns were established** which led to more settled and easier management when the child or young person was home on the weekend and during holidays.

3. **Routines were established** and followed at home which reduce some of the incidence of challenging behaviours including aggression.

4. **Toilet training was improved** and in some cases the young person became independent and no longer required nappies.

5. The young people were able to **develop their own friendships** and socialise in ways which had not before been possible so that parents felt their children were part of an active community:

   For the first time in his life he chose his own friends, like normal people do. And they weren't the boys in his class and they weren't the boys in his house, they were other boys that he chose. (Elizabeth, mother)

   So the hostel had a few things going, there was a little community, you know, they'd have their little discos or they'd have, you know, something afterwards so that community thing was good. (Tammy, mother)

   Because, you know, they'd have movie nights … they'd have movie nights, they'd sit around in their pyjamas and have popcorn. There's no way my son out in the community would ever …have that experience. (Elizabeth, mother)

6. Parents were freed during the week to **pursue and maintain employment** and socialise with friends and relations. It also meant, for some, embarking upon or completing studies:

   … when Peter started at Kingsdene I went back to Uni and I did the Grad Dip. for teaching. (Amelia)

   … and I went to study, did my Masters through that. That was opportunity, an opportunity I wouldn't have otherwise had… things like that; so I owe that to Kingsdene that I was able to do that. (Sarah)

   You know somebody would ring me up and say "Come and have a cup of coffee with me" and I'd think "I can't". But then I thought "oh, yeah I can. Ben is at Kingsdene".

7. Parents reported a **significant reduction of stress**, feelings of depression and despair once their child was settled at Kingsdene:

   I would not have survived emotionally; physically I was exhausted. (Evelyn, mother)

   … we were just totally exhausted and yeah, Kingsdene came at the right time. (Tammy, mother)

8. Siblings and parents reported that the mid-week respite enabled them to develop **more supportive and stronger parenting links with their other children**. It gave parents time to focus on their other child's schooling, their friends and their sporting activities. It also enabled siblings to invite friends home from school and to feel as if they were coping more adequately with life. It

even meant some families could have short breaks and holidays away together:

I was able to concentrate on my son and that he got a reasonable quality of life, we got a reasonable quality. (Tammy, mother)

… it allows siblings to develop without being predestined to anxiety, failure to achieve all of that. (Margaret, mother)

I could spend time with the other children. We could take them to ballet, music, sports and you know … things that we can't do when Simon is around. So, yeah, at that time, that few years well we could function much better. (Letitia, mother)

The collective opinion of participant parents and siblings in ANGLICARE's study was that the residential school model was both successful and beneficial to every family member, and is a model which should continue to be provided for other families in similar circumstances:

The Kingsdene model …allows siblings to develop without being predestined to anxiety, failure to achieve all of that... for the ones that need it it's almost do or die … for God's sake keep it going for young families, give the siblings a chance. (Margaret, mother)

Others wished to emphasise that a school such as Kingsdene is not an 'institution' in the usually accepted sense:

… it is the most exquisite, beneficial place where children like my son blossomed … (Elizabeth, mother)

… it's the one that if done properly as Kingsdene was, has fantastic benefits and fits a desperate need in a sector of the disability community and is missed and we get a little bit disappointed with some of these advocates that go out saying "Disabled people

should be with their family and they should have proper support" and all of that. (Ross, father)

We want to say "Thank you" to Kingsdene and all that. It's so sad that Kingsdene closed … because it really helped us, didn't it? (Janice, mother).

The residential school model was both successful and beneficial to every family member.

Policy makers should consider the value of residential shared care arrangements for children who experience significant intellectual disability combined with challenging behaviours. The evidence regarding Kingsdene collected through ANGLICARE's study and overseas experience indicate that there are significant benefits for parent carers, for siblings and for the child with an intellectual disability from such a model.

7.4 A NEW FUTURE – THE NATIONAL DISABILITY INSURANCE SCHEME

In August 2011 the Productivity Commission delivered its final report into disability services and support in Australia. The report proposed a major overhaul of the arrangements for disability support and the establishment of a National Disability Insurance Scheme (NDIS) to address chronic underfunding and inequity in the current service arrangements. Reform and adequate funding for the whole of the sector was urgently required to provide a proper level of care and support for people with a disability and their carers, so that they might achieve an enhanced quality of life and increase their economic and social participation in Australian society.

The key to the funding model is individualised funding packages which are portable and would

support people with a lifelong disability. As needs change so too would the levels of funding. The NDIS is currently being piloted in several regions throughout Australia. It is anticipated that it will be fully rolled out by 2019. It represents a massive injection of funding into the sector.

The range of supports offered include physical aides and appliances, personal care, domestic assistance, respite, home and vehicle modifications, community access, transport assistance, specialist employment services, specialist accommodation support, therapies, case management, crisis/emergency support and guide dogs and assistance dogs.

For families caring for children with a significant intellectual disability coupled with challenging behaviours the new NDIS funding model has the potential to resolve a number of issues – most importantly – it will not be a 'one size fits all' approach. It is to be hoped that the severity and complexity of the issues which these young people face will be adequately addressed with the new NDIS model. As some parents reflected:

… the Kingsdene children in general, they're not typical of the ten thousand that are on the waiting list. A lot of those people on the waiting list … can actually catch a bus themselves. They can do their own medication, they can do their own cooking, feeding, self care, whereas Peter does none of that. (Margaret, mother)

You know if Ben was mildly intellectually disabled and able to do things for himself, able to be alone by himself and, you know, for five or ten minutes while I went out or to play by himself, just to amuse himself, then you know my life would be so different. But he's not. He's not able to… Nobody makes the distinction between it. And it really does have to be made. It really does have to be made. (Evelyn, mother)

In order for the model to work well with this particular cohort however, a number of factors would need to be present:

1. **A reduction in the amount of paperwork and consistency in service delivery among service providers.** Participants in ANGLICARE's study found these to be significant issues with the current system:

   … things like epilepsy management plan, you know, … five different places want five different plans, I mean it's not coordinated. Why cannot they accept one form? But that's where the issue is. (Tammy, mother)

   … there are some weeks where all I do is go back and forth to the doctor because she's got to fill the things out and it's just never ending. (Kathryn)

   Each year you have to get all this medical stuff reviewed … they all require you [to] go back and you get the doctor to fill out umpteen forms when nothing has changed and nothing probably is going to change, and yet you've still got to do that over and over and over again and it does, I find that just so frustrating … (Mark)

2. **Availability of adequately remunerated, well trained staff** because parents reflect, at the moment, that:

   … unfortunately people who provide care don't get paid enough. It's really hard to get good staff. (Evelyn, mother)

3. **Development of services which understand and know how to deal with children and young people who exhibit both significant intellectual disability and challenging behaviours.**

4. **A flexible model of service provision,** tailored to suit the individual needs of both the young person with the disability and the family as a whole. In this research project a number of

participants expressed frustration at being forced to 'fit' into a service model, as opposed to having the service model personalised for their family's requirements:

Every person has a different need. (Ray, father)

The one model is not … for everyone. (Tammy, mother)

5. The new model also needs to provide **easy access to information on the range of services available** with professional and appropriate assessment to determine the level of need. Navigating the system needs to be relatively easy with special consideration given to those from non-English speaking backgrounds:

I think it's very fortunate that we had, we were well resourced, well educated and articulate, intelligent people and it was still a really big struggle for us… So I think that if it was a struggle for us I can only imagine how much more difficult it is when you don't have those advantages. (Hugh, brother)

6. **The opportunity to have access to periodic intensive support services** if and when required, as life circumstances change.

8. CONCLUSION

This report has found that the situation for Australian families, where one member is profoundly or severely intellectually disabled, is one of daily hardship and stress in every area of life. The young person with an intellectual disability requires high levels of assistance with eating, toileting and other personal care tasks. Challenging behaviours such as aggression, destructive behaviours and poor sleeping patterns affect all members of the family, leaving them injured, fatigued, vulnerable and stressed.

Parents struggle with both physical and mental health problems, marriages continue under excessive strain, employment and career advancement opportunities are limited, and the overall financial position of the families is reduced. Siblings experience lack of parental input, shame and social isolation.

Family outings are either highly modified or simply non-existent, due to the overwhelming difficulty of working around the needs of the person with a disability. Support from extended family is reduced, and friends withdraw, unable to understand the unique circumstances in which these families have found themselves. Provision of medical attention for the person with a disability becomes a tortuous and complicated process.

Families attempt to access respite care, but find that the services are difficult to obtain and limited in the behaviours which they are prepared to accept. Services which are currently available are perceived as either insufficient or inappropriate for the particular needs of young people with severe intellectual disabilities. Parents have spent years battling for services for their children, and have been exhausted by the process. The necessity for relinquishment in order to gain supported accommodation produces additional emotional turmoil.

For the families in ANGLICARE's study, the highlight since the birth of their child with a disability has been the attendance of those children at Kingsdene Special School, which provided skills training and social interaction for the children, and enabled family members greater freedom to engage in employment, study and homemaker roles, for at least part of each week.

Residential care, such as was provided by Kingsdene Special School, has not been viewed in a positive light by policy makers in Australia for some time. It seems it was considered that, since many of the older institutions were horrendous (a fact which is not disputed in this report), the concept of large-scale residential care *per se* must therefore always be viewed in a negative light. However, in the opinion of those parents who needed to send a child to Kingsdene Special School, this residential school was the single most important and helpful service option that they have experienced.

The highlight since the birth of their child with a disability, has been the attendance of those children at Kingsdene Special School.

The concept of residential care does not automatically mean a return to the disgraceful conditions which existed in the large institutions for those with intellectual disabilities which were rightfully closed in the 1980s. The concept of grouping people with intellectual disabilities together as a peer group need not be viewed negatively; for example, retirement villages and boarding schools are examples of socially acceptable groupings of peer groups in residential settings.

Government policy regarding care for people with intellectual disabilities must take into account the needs and wishes of those people and their families – not to mention their accumulated wisdom over many years of raising a child with a disability. This report has demonstrated that what is most desirable are individually designed care packages which will provide the relief and assistance that these families so richly deserve. In addition, those packages need to include a range of service options from which families may choose for themselves, with each option being easily accessible and available, thus eliminating the need for a lifelong experience of negotiation and advocacy on behalf of their family member with a disability. It is hoped that the new National Disability Insurance Scheme will go some way to meeting these needs.

9. RECOMMENDATIONS

The basis of the Federal Government's NDIS is that people with a disability have the right to appropriate individual support and choice in relation to the provider of that support. In the light of this new national approach and the findings of the ANGLICARE study, it is recommended that:

1. The **New South Wales Government** provide funding for the residential special school model, as exemplified by the Kingsdene special school, in order to expand the education and accommodation options available to children with an intellectual disability and to provide a much-needed respite option for carers and families of children with profound and severe intellectual disabilities.

2. In view of the funding levels required for the residential special school model, that the **NSW Government** retain block funding of such a model, in part or in full.

3. In implementing the NDIS, the **Federal Government** have special regard to the needs of people with severe and profound intellectual disabilities and their carers. In this respect, the following issues are highlighted to ensure that the scheme will address the needs of this group:

   i.   The need for reduced 'red tape' and consistency in service delivery among service providers.

   ii. Availability of adequately remunerated, well trained staff

   iii. Development of services which understand and know how to deal with children and young people who exhibit both significant intellectual disability and challenging behaviours.

   iv. A flexible model of service provision tailored to suit the individual needs of both the young person with the disability and the family as a whole.

   v.   Easy access to information on the range of services available with professional and appropriate assessment to determine the level of need.

   vi. The opportunity to have access to periodic intensive support services if and when required, as life circumstances change.

4. In providing support packages for people with an intellectual disability, the **Federal Government** through the NDIS take into account the needs of parent carers and siblings. In this respect, a separate assessment of carer and sibling needs should be undertaken.

5. It is noted that the move towards individualised funding packages will not provide funding for the training of staff. Therefore it is recommended that both **Federal and State Governments** provide funding for staff training for specific additional skills to work with people with an intellectual disability who also have challenging behaviours.

APPENDIX

INTELLECTUAL DISABILITY FOUND AMONG KINGSDENE CHILDREN

The key criteria for defining intellectual disability include: significant impairment in intellectual functioning; difficulties in adaptive behaviour; and manifestation in the developmental period (Luckasson et al. 1992, 2002).

In the past twenty years, the concept of intellectual disability has expanded to place increasing importance on functional and environmental considerations and less emphasis on individual deficiency. Such approaches move beyond the reliance on IQ scores to define intellectual disability and rate its severity. Conceptualising intellectual disability in terms of need, support and services certainly helps to foster consideration of the plight of the families and carers of people with profound intellectual disabilities as being both commendable and challenging.

As an example, the two most recent editions of the manual of the American Association on Mental Retardation (AAMR) introduced a new concept of 'intensities of needed supports' to replace the formal classifications of severity using IQ scores. This approach to measuring severity is more functionally relevant and oriented to service provision and outcomes (Luckasson et al. 1992, 2002). This means that the measure of IQ scores and functionality as well as the need for support is now used to differentiate mild from severe intellectual disability (WHO, 1992).

Of those under the age of twenty who have an intellectual disability, 68,900 have limitations and restrictions which are classified as being severe or profound (AIHW, 2008). Someone with severe or profound intellectual disability has an IQ of less than 35. They may recognise familiar people and have relationships with important people in their lives.

However, they have little or no verbal communication skills, use gestures to communicate and require lifelong assistance with personal tasks and in every area of their lives (Centre for Developmental Disability Health, 2012).

Within the population of intellectually disabled people, 54% acquired their disability as a result of a genetic disorder and 17% are classified as having acquired their disability as a result of 'disease, illness, or hereditary disorder' (AIHW, 2008:11). Fifty-seven percent have a co-morbid psychiatric condition, and just less than 50% also have a physical or diverse disability (AIHW, 2008). This would mean extra care demands for those looking after them.

Information concerning the incidence of particular diagnoses is both patchy and scarce. For example, researchers have attempted to establish prevalence rates for diagnoses of autism spectrum disorders in Australia, collecting data from Centrelink, the Australian Institute of Health and Welfare and Autism and Disability associations. Williams et al (2008) found that, due to the vast and differential variation in prevalence rates reported between the various states, territories and recording agencies, the precise figure/estimate/incidence of autism spectrum disorders within Australia cannot be accurately estimated.

Within the Kingsdene cohort of young people there were a number of syndromes, five of which are described below:

- **Angelman syndrome:** In 1965 an English doctor, Dr Harry Angelman, described characteristics he had observed in three young children; later these characteristics were attributed to a genetic disorder named after him: Angelman syndrome. People with Angelman syndrome always exhibit

developmental delay, severely impaired speech, movement disorders (including unsteady gait), toileting problems and 'behavioural uniqueness' (such as laughter, smiling and being over-excitable). Over 80% have very small heads and suffer from seizures. A multitude of other characteristics may be present: drooling, sleep difficulties, feeding difficulties, stereotypies (especially hand flapping) and attraction to water (Angelman Syndrome Association of Australia, 2012; Horsler and Oliver, 2006).

- **Autism Spectrum Disorders:** A diagnosis of autism is made when certain behaviour patterns have been observed or described in a person; most commonly, in males. These patterns fall under three broad headings: social impairment, communication difficulties and repetitive behaviour. While some people with an autism spectrum disorder (for example, those with Asperger's syndrome) function at a relatively typical level, around 70% of those with autism also have a level of intellectual disability. There are some distinct syndromes which include autism as part of their diagnostic characteristics. These include Angelman, Smith-Magenis, Rett, 22q13 and Fragile X Syndromes, and Tuberous Sclerosis (Centre for Developmental Disability Health Victoria, 2010; Cohen et al, 2005).

- **Cornelia de Lange Syndrome:** This syndrome is named after the Dutch doctor, Cornelia de Lange, who described a set of symptoms she observed in several children in 1933. It has since been identified as being the result of specific genetic abnormalities. The physical presentation of this syndrome includes general small physical size, delayed growth, microcephaly, distinctive facial features (for example, thin eyebrows which join above the nose), excessive body hair, malformed organ systems, gastrointestinal tract problems (such as reflux) and developmental delay. Self-injurious behaviours are common in people with

Cornelia de Lange syndrome, and it has been found that between 62% and 74% of sufferers also have some form of autism spectrum disorder (Cornelia de Lange Syndrome Association of Australia, 2012; Wulffaert et al, 2009).

- **22q13 Deletion Syndrome:** This syndrome is caused by a chromosomal abnormality, and was only defined as a separate, identifiable syndrome in 1994. Babies with this syndrome are observed to be 'floppy' due to lack of muscle tone, and hence they are delayed in reaching the usual developmental milestones. These children eventually walk, but with an unstable gait; they lack speech development, and display tongue thrusting and grinding of teeth. There are usually distinguishing facial anomalies, for example, puffiness around the eyes; some may also have anomalies of the hands, feet or head. They have moderate to severe levels of intellectual disability, and over 90% have some characteristics of autism (Havens, et al, 2004).

- **Rett syndrome:** Rett syndrome is found almost exclusively in females, and was first identified in 1966 by an Austrian physician, Dr Andreas Rett. Generally there are no abnormalities observed during the first six months of life; between six and eighteen months children lose both fine and gross motor skills, communicative skills and cognitive abilities. In addition, it is during this period that they also develop microcephaly, autistic features and various stereotypical hand movements such as patting, beating or clapping. Between 70-80% of people with Rett syndrome also suffer from epileptic seizures (Brain Foundation, 2012; Ibrahim & Khan, 2008).

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Raising a child with a profound intellectual disability can involve managing a range of challenging behaviours. These behaviours include aggression, self injury, destructive behaviour, sleep problems and repetitive behaviours (stereotypies). The research in this new report from ANGLICARE Sydney reveals that the caring role combined with challenging behaviours can have substantial impacts upon the physical and mental well-being of parents and upon their marital, working, financial and social lives. There are also a range of impacts felt by other siblings of the child with a disability.

This research was inspired by ANGLICARE's experience in running the Kingsdene Special School and the stories of the 'Kingsdene families' who were part of the school. The report shows why residential special schools are a beneficial option both for parents and children and should be available for children with severe intellectual disabilities. The report calls for Government funding to be made available for this important work.

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