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Children and young people with disabilities (incorporating challenging behaviour)

Family resilience where families have a child (0-8 years) with a disability: Final short report

Report Prepared for the Disability Policy and Research Working Group

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1 Introduction

In September 2006 the Disability Policy and Research Working Group[1] engaged the Social Policy Research Centre (SPRC) at the University of New South Wales to complete a research project entitled 'Children and Young People with Disabilities (Incorporating Challenging Behaviour)'. The research aims to increase the understanding of family resilience in families where a child (0-8 years) has a disability and to inform service provision.

To this end, a qualitative methodology was designed for use in researching family resilience in families who have a child aged 0-8 years with a disability. The research was conducted in two parts – a literature review and primary data collection with families (where a child 0-8 years of age has a disability) and other key stakeholders, such as service providers, family advocacy groups and government officials.

The literature review (Muir 2006) defined and described the term 'family resilience' as it relates to families who have a child aged 0-8 years with a disability. It examined how this understanding of family resilience could be integrated with service provision and the affect service providers and professionals can have on families and the challenges of implementing family resilience research into practice. A descriptive framework of practice elements that service providers and professionals can use to assist families to maintain, build and strengthen family resilience in families where a young child has a disability was also provided. Finally, the literature review explored the practicalities of measuring family resilience where a family includes a child with a disability (0-8 years). It looked at the challenges, problems and limitations for practitioners when attempting to measure family resilience and the reliability of these tools.

This short report summarises the findings of the final report, which focuses on the findings from the primary data collection with families and stakeholders. It develops the understanding of family resilience in families with young children (0-8 years of age) with disability. This component of the research also analyses service practices and models in order to identify and define elements of practice that build family resilience, detract from family resiliency, and are crucial to the maintenance of resiliency. It concludes with a section on how services can assist families to build and maintain resilience. This report should be read in conjunction with the literature review and, for a more detailed understanding of the research findings, the final report.

[1] The Disability Policy and Research Working Group is a working party to the Community and Disability Services Ministers' Advisory Council which discusses Commonwealth State Territory Disability Agreement management issues and oversees the development and implementation of the Commonwealth State Territory Disability Agreement work plan (http://www.facsia.gov.au/internet/facsinternet.nsf/disabilities/policy-cstda.htm).

2 Methodology

A qualitative methodology was used to develop an understanding of family resilience in families where a child aged 0-8 years has a disability. Interviews with families and key stakeholders were conducted to determine elements of practice that facilitate and detract from family resilience.

2.1 Family Interviews

Eleven families where children under eight years of age have a disability were interviewed in March and April 2007. The recruitment of families captured a range of families from different demographic backgrounds (Table 2.1). The descriptions of individual families are found in Table 2.2.

Table 2.1: Family interviewees by interview type and demographic detail

Characteristic		Number
Total families interviewed		11
Face to face interviewees		8
Phone interviewees		3
Children with disability under 8yrs included in data		12
Children with disability aged:	2 years or younger	4
	3-4 years of age	4
	5-7 years of age	4
Other children with disability in households over 8yrs		6
Family member(s) interviewed:	Mother only	7
	Father only	0
	Mother and father	3
	Foster Mother	1
ATSI families		2
Sole parent families		3
Families primarily reliant on government benefits		3
Geographic area:	Urban	4
	Regional	3
	Rural	4

Table 2.2: Description of family participants[2]

Gabby and Brad	Gabby is a sole parent with four children living in an urban area. Her youngest child, Brad (3 years of age) has been diagnosed with a cognitive impairment. Two of Brad's siblings also have speech, behaviour and learning difficulties.
Naomi, Bill and Ingrid	Naomi, her husband Bill, and Ingrid (an only child) live in an urban area. Ingrid (2 years of age) is deaf, has cerebral palsy and some cognitive impairment.
Kelly, Robert and Jasmine	Robert and Kelly live in rural NSW. They have three children. Jasmine (6 years of age) was diagnosed with Down Syndrome when she was one day old and also has dysphasia.
Carrie, Joshua and Hank	Carrie, Joshua and their three children live in remote NSW. Hank (2 years of age), their youngest child, has cerebral palsy.
Jacinta, Alex and Artie	Jacinta and Alex have one child, Artie (five-and-a-half months old), and live in urban NSW. Artie has Down Syndrome.
Shelley, Michael and Gisha	Shelley, Michael and Gisha (2 years of age) live in regional NSW. Gisha has cerebral palsy, epilepsy, an intellectual disability and is blind due to a brain injury resulting from foetal distress at the time of birth.
Amy and Angus	Angus (4 years of age) lives with his foster family (Amy, his foster mother, foster father and three foster siblings). Angus, who has cerebral palsy, has lived with his foster family since he was 13 months old. Angus, his foster father and siblings are Aboriginal.
Liana, Zach and Ian	Liana is a sole parent with four children living in a rural area. Two of her children have a disability - Zach (7 years old) and has a global developmental delay and Ian (5 years of age) has non-verbal autism.
Abbey and Ben	Ben (3 years of age) is the youngest child in a couple family with three children. He has hemiplegia, cerebral palsy and developmental delay as a result of a stroke after birth. His brothers are 8 and 11 years of age.
Margaret, Mitchell and Georgia	Margaret is a sole parent with five children (Ryan, 13, Emily, 11, twins Mitchell and Georgia, 5, and Tom, 4) living in a rural area. Mitchell has autism and Georgia has Asperger's Syndrome. Their brother, Ryan, also has Asperger's Syndrome and bipolar disorder.
Karen and Rachel	Rachel (almost 3 years of age) lives with both parents and one sibling in a regional town. Rachel was diagnosed with Tuberous Sclerosis 11 days after she was born. She has benign tuber growths in her brain, which cause epilepsy, and low muscle tone.

2.2 Stakeholder interviews

Key stakeholders were identified by the research team in close collaboration with the Disability Policy and Research Working Group's project Steering Committee. Contact was made with 17 potential stakeholder participants, of which ten consented to be interviewed. Two participants requested the participation of colleagues, resulting in a final total participant number of thirteen. The stakeholders included representatives from advocacy groups, service providers from government, non-government and private organisations and government officials at the policy level (Table 2.3). The key

[2] To maintain the privacy and confidentiality of the families interviewed, names have been changed and geographic locations removed.

responsibilities of individual stakeholders (Table 2.3) and the groups of stakeholders (Table 2.4) are described below.

Table 2.3: Service provider participants

Role in organisation	Service sector	Service location
Project development	State Government	Tas
Service development	Federal Government	Federal
Family representation & advocacy (and parent)	Family Advocacy	NT
Programs management	State Government	QLD
Service development	State Government	QLD
Family representation, advocacy and leadership development (and parent)	Family Advocacy	NSW
Management of Policy & stakeholder liaison	Federal Government	Federal
Training in Inclusion and professional support	State Govt service development	ACT
Director, respite care	Service development & provision (NGO)	SA
Performance and quality control; management	State Government	Tas

Advocates

Two family advocates provide parental support, information, referral and advocacy (such as service development and government policy). Both advocates listed various activities undertaken to promote leadership and skills acquisition among families.

Service providers and developers

Three respondents provide services directly to families, or support or train other service providers who do so. Two respondents work in Government organisations and have direct experience with families. The final two respondents are involved in respite care services and one provides professional support to childcare services concerning inclusive practices.

Government officials

Government stakeholders (five State and four Federal) work in policy and project management in a number of disability and family branches. They were responsible for funding supports and services, policy development and/or the development and implementation of service delivery models and strategies.

Table 2.4: Responsibilities of stakeholders

	Advocacy groups	Service providers & developers	Government officials
Macro-level policy development			x
Service-level strategy development		x	x
Referral	x	x	x
Information	x	x	x
Direct funding			x
Direct service provision		x	x
Advocacy, representation	x		
Empowerment, leadership training	x		
Professional training and support	x	x	x

Data Analysis

Data from the family and stakeholder interviews were analysed using the following method. Each interview was coded according to the interview schedule, data was examined access interviews, coding for shared themes, researchers met to discuss, verify and confirm convergent emergent themes and coded were analyses for theoretical intersections and links.

3 Understanding family resilience

This section explores the process of family resilience, how families where a young child has a disability function, the factors (resources and strengths) that protect families and issues that threaten resilience.

The literature demonstrates that family resilience is not a trait, static entity or an absolute. It is a process that will change over time and exist on a continuum of levels. Family resilience where the family includes a child with a disability can be described as a process that includes three steps:

- crisis/adversity;
- drawing on strengths and resources to adjust; and
- adapting and resuming family functioning adversity, resources/strengths and adaptability.

When confronted by adversity, families draw on their strengths and resources – those internal to the family and individual family members and external resources such as services – so they may adapt to the situation. The family is able to recover from the adversity; they are able to regain a pattern of family functioning, despite having to make some changes. Furthermore, this outcome is one that families are able to achieve and maintain. Family resilience can shift and change over time.[3]

Stakeholder interviews sought to explore what 'family resilience' means for them.

Stakeholder perceptions of family resilience

Stakeholders consider 'family resilience' to mean:

- intra-individual and intra-family qualities that get them through times of significant crisis and day-to-day challenges of disability and family life;
- the ability to 'bounce back';
- equity of access to opportunities;
- freedom of choice; and
- adequate external supports.

Overall, the responses of stakeholders reflected the intrinsic relationship between intra-individual and intra-familial strength and the supports they receive – from their own communities and from the disability and broader service sector.

[3] For further discussion about family resilience see Muir, K. (2006). *Family resilience where families have a child with a disability: literature review*, Report prepared for the Disability Policy and Research Working Group, Sydney, Social Policy Research Centre, University of New South Wales.

Family case studies: facing adversities and stress

The families interviewed were all going through the process of resilience to varying extents. They experienced numerous occasions of adversity, crisis or very stressful experiences; they were constantly reacting to these situations and having to renegotiate routines and restabilise family functioning. All of the families spoke of experiencing crisis and adversities associated with particular events, including:

- birth;
- diagnosis and assessments;
- accessing services for their child with a disability;
- hospitalisations (emergency and planned);
- therapies and treatments;
- financial pressures; and
- the compounded effect of having other family members with high level needs.

Parents, mothers especially, also reported being under stress from a lack of sleep due to the extra demands of caring for their child with a disability.

Family functioning

Family functioning plays an integral role in family resilience. Most of the interviewees reported that the family's functioning often revolved around the child with the disability; they were frequently negotiating the resilience process by changing or adapting their family functioning.

Work and education

Work and education commitments ensured some levels of family functioning remained fairly stable, at least for the family members involved in these activities. In all of the couple families (except one, where the responsibility was shared), the fathers were the primary income earners.

Generally the fathers' working week routines remained relatively stable compared to their partners. However, having a child with a disability impacted on some fathers' decisions regarding their employment. Fathers' work demands also increased the burden of caring responsibilities on mothers, in particular increasing the difficulties of caring for their child with a disability.

Only a few of the women interviewed were working. One was able to work full-time because of the flexibility of her and her husbands' employers. The other two women working did so part-time. Mothers' work was important in:

- balancing out mothers' needs;
- providing some stability and routine to the week; and

- providing additional income to enable their children with disability to partake in activities that all children have the opportunity to participate in.

Caring responsibilities

Unsurprisingly, caring responsibilities dominated most routines and how the families functioned day-to-day. Routines for the mothers with young children largely revolve around early intervention and therapy appointments. While there are often specified days for appointments, the list of therapies coupled with essential, unplanned medical appointments, illnesses or behaviour problems, mean it is difficult for families to maintain steady routines. Caring responsibilities and medical problems can also interrupt work and education commitments, particularly for mothers. Families experience a constant renegotiation of family functioning.

Many of the mothers interviewed highlighted the extensive time demands placed on them. When children are young, it is difficult for family functioning to not revolve around the child's disability. Once children are school aged, maintaining some routine becomes somewhat easier for some families because some routines are determined by school times.

Family adversity, functioning and resilience:

- Families all described experiencing the resilience process;
- Families experienced many periods of adversity (both related and not related to disability); and
- They were constantly renegotiating family functioning as a result of reacting to changing circumstances in relation to their child's disability.

Protective factors: resources and strengths[4]

The resources and strengths families have to draw on are essential in assisting them to maintain resilience: to overcome adversity, to adapt family functioning and re-establish normal routines.

Problem solving

All family members interviewed, except one, identified good communication as a strategy for solving problems within the family. These discussions occurred between partners and partners and children. The families' belief that they have the capacity to

[4] Spirituality and 'finding meaning' were two other issues identified. However, these were issues for few families and were not described in great depth. Thus, they comprise short sections of the full report and are not discussed in this short report.

solve problems was often determined by whether they felt the problems were within or outside their control.

Balancing family relationships

Balancing the needs of all family members (not only the child with the disability) was a challenge for most of the families interviewed. The hierarchy of meeting family members' needs was generally addressed in the following order: the child with a disability, siblings, individual parents (often the father first) and couples.

In all situations the mothers were the primary carers for the children. In a few situations, there was a clear delineation of roles. Therefore when extra caring demands were placed on them, women in these situations often absorbed the extra responsibilities, leaving them little time for themselves.

In other family situations, fathers took on more responsibility to provide their partners with time away from the children. However spending time together as a couple was then compromised. It was identified that many new families experience this, but it could be more pressing for families where a child has a disability because of the additional demands required in baby-sitting. Family holidays were identified as being really important for families to 're-connect'. This was not an option for sole parents, who expressed particular difficulties in finding time for themselves and financial resources for holidays.

Addressing the needs of siblings was prioritised, but parents also found this to be a challenge because of the time required to care for their child with a disability. All of the mothers reported that their other children 'miss out' in terms of receiving sufficient attention and having their needs met. This had implications for siblings' behaviour, their capacity to be involved with their friends and participate in the community, particularly for those in rural areas.

Parents attempt to spend time with their other children when these children 'don't have to compete' with their brother or sister with disability. Some parents are battling to balance instructions from therapists with the needs of their other children. The other issue raised by three families in regard to siblings was their role as young carers. The supportive caring roles siblings play are an important resource for parents, yet parents are also mindful of the responsibility and time constraints this can place on their children. Balancing other children's educational needs, social needs and family responsibilities was a concern for parents interviewed.

Hardiness/durable

Another protective factor is having a family that works together in difficult times. All families identified some emotional strengths and tangible strategies that they believe make their families durable. Traits such as being 'cohesive, self-sufficient, optimistic' and 'in it together' were mentioned. Couples reported having strong relationships that are 'lovable, close and affectionate'. Parents also drew on the strengths of other family members. Not all families believe they are durable and, in some cases, partners do not always agree about the family's hardiness. Two mothers reported that their families are sometimes able to endure difficulties and other times not.

Social support

Maintaining relationships with relatives, friends and others to keep up social interaction, avoid social isolation and ensure a network of people who can provide practical and emotional support when required can also protect families.

Informal support from extended family members and/or friends is a common source of support for most of the parents interviewed. This support ranges from emotional to practical support, such as financial assistance and child care.

All of the couples cited each other as their main emotional support. They generally reported friends or extended family as the second most common supports and thirdly support groups, such as on-line or community based disability specific groups. The sole parents interviewed rely on friends, extended family and services for their emotional support. Two sole parents, however, appear to be dislocated from their local communities because they are not emotionally or socially linked with other members of their community.

The women in couple families (with the exception of one) were able to readily identify at least one source of emotional support besides their partner. However the fathers involved in the interview process reported not having anyone other than their partners to talk to about issues raised by having a child with a disability.

Even those families who have informal support available cannot rely on that support when they most need it. This is an important issue for resilience and service provision; families with informal contacts still need extra support. Most respondents reported not being able to rely on extended family members**.** Fear, a lack of behaviour management skills, geographic separation, poor health and a preoccupation with their own responsibilities were some of the reasons the interviewees gave for their extended families' lack of support. Even where practical support was available from one side of the family, there was some anxiety around the permanence of this support, due to their parents' ageing or geographical distance.

Friends are less likely to be primary supports for most of the interviewees. Some interviewees are reluctant to ask friends to help with child care for their child with a disability because of the extra demands of care, their own family responsibilities and ignorance of how to treat and care for the child with a disability. Friends are helpful emotional supports and babysitters for other children.

Routines and family times

All families interviewed had periods of time they spent together, such as over meals, at church, going on picnics or holidays and doing other family based activities. While spending time together was found to be beneficial for families, it could also present challenges, conflict and/or stress if activities were affected by the child's disability. Behaviour problems limited the capacity of some families to interact socially or attend certain community events. Parents restrict the places families attend for social events to ensure there is no danger to their child.

Couples are more able to balance weekend activities for the range of their children's needs because they can split up responsibilities. Where older siblings can take on caring responsibilities, families have greater flexibility to participate in activities. Sole parents were more socially isolated because taking their children, including their child with a disability, out on their own was difficult.

Hope and flexibility

Stakeholders noted that when children with disabilities are going through diagnosis, assessments and disability management plans, their wishes, dreams and aspirations for the future sometimes 'get lost'. Maintaining these and working towards achieving them are considered by some stakeholders to be a central component of family resilience. These aspirations translate to future-oriented concrete, practical concerns and are linked in some way to the child's development and progress.

Most of the families interviewed have goals or hopes related to their children, such as being able to access required services and supports and for them to get a sound education. Most families hope for happiness, for their families to remain strong and for the needs of individual family members to be met. Some families just hope for a break away from the routine of therapies. While practical support may assist families to set and achieve some goals, there is less hope around goals for financial security. Relying on government support and having to limit employment due to caring responsibilities and the lack of appropriate child care can place limitations on the long term financial goals of families.

Financial management

The comments from stakeholder and family interviewees suggest that financial management and adequacy of income are important factors for families who have a child with a disability. The majority of the families interviewed cannot always afford the goods and services they feel are essential for their child with a disability to achieve a reasonable quality of life. Two families can 'rarely' afford these goods and services and five can only 'sometimes' afford them. The remaining families reported being able to afford goods and services most of the time or all of the time, but nonetheless expressed concerns that their situation may suddenly change. They also described careful decision-making concerning their finances.

Openness

Most parents interviewed actively spoke with their children about what their sibling with disability 'can and can't do'. One parent found it difficult to help her children understand their siblings' disability, and two parents stated they do not communicate well as a family. Couples also reported talking 'openly' with each other about how their child is going and about parenting. As the mothers are the primary carers and largely going to doctors alone, they often informed their partners about their child's clinical outcomes.

Empowerment

The level of empowerment of the parents interviewed is difficult to judge. However, parents articulated their feelings of control, or lack of, when dealing with service

providers. In dealing with difficult services, one couple uses a 'good cop, bad cop' strategy, in an attempt to bring the situation under their control and successfully negotiate.

Health

If adequate support services cannot be accessed or are unavailable, a family member's poor physical and/or mental health has the potential to unseat most of the factors listed as critical in protecting and strengthening these families. All except one individual reported their health as good or very good at the time of the interview. However, one of the women who reported good health believes she 'may be suffering from depression'. A few of the parents interviewed exercise for stress relief, but not all can allocate the time for regular physical activity.

3.1 Issues that Threaten Resilience – Risks for Families

When asked about the risks they see their families possibly facing in the future, none of the families stated that they are concerned that their families will separate or relinquish their child.

The families' own concerns for their future include:

- issues associated with their child with a disability getting older: schooling, increased weight and being able to carry them, about the time when their children were 'not as cute';
- future health problems and safety for their child with a disability;
- who will care for their children when they are no longer alive;
- barriers associated with their geographic location and/or having to move to accommodate their child's needs or financial concerns;
- loss of financial security and/or increasing financial stress;
- difficulties in accessing services in relation to supporting their child with a disability; and
- the limitations imposed on their other children and the risk of their needs not being met.

Family protective and risk factors:

- Having resources and strengths to draw on protects families and helps them recover and experience resilience;
- Families are most likely to use communication, emotional strengths and tangible strategies to deal with stress, solve problems and manage interfamily conflicts;
- Most families have difficulty balancing the individual needs of family members because of the time and financial resources required to support their child with a disability;
- Couples spend little or no time alone together and sole parents have little or no time for themselves and appear dislocated from their local communities;
- Families are stressed about trying to address the needs of their children who do not have a disability;
- Sole parents and fathers are most likely to lack emotional support;
- Despite all except one family identifying sources of informal emotional or practical support, seven families reported not getting support when they most need it;
- Families sometimes socially isolate themselves because of barriers – financial, behavioural, transport, extensive caring – faced as a result of having a child with a disability;
- Family interviewees hope for long-term goals, like positive outcomes for their children, and short-term ones, such as access to necessary services and supports;
- The majority of families can not afford the goods and services they believe are essential for their child to achieve a reasonable quality of life;
- Most interviewees reported sound health; but the interviews reinforced the importance of emotional support for families; and
- Families worry about future access to services, their ability to cope with a child with a disability as they get older, their financial security, geographic location and about their other children's outcomes.

4 Service Provision and Family Resilience

The purpose of this section is to integrate findings from stakeholder and family interviews that offer insight into the characteristics of an optimal service provision framework, which supports family resilience.[5]

4.1 Formal Services and Supports used by Families

The families interviewed use a range of formal services and supports which can be categorised into community, disability specific, co-ordinated, medical, therapy, family focused and other government services. All families access a range of medical services, however, there is considerable discrepancy regarding access to other types of services. Table 4.1 shows the range of services people access and gaps in their service provision.

[5] The following Section, Section 5, deals with *how* services can assist families to build and maintain family resilience.

Table 4.1: Current service use by service type and family

	Community services	**Disability specific service**	**Co-ordinated supports**	**Medical services**	**Therapy**	**Services focussed on other family members**	**Other government supports/services**
Jacinta, Alex and Artie	Child care (3 days/ wk)	One disability specific service	Lifestart (physio, group therapy child care aide)	GP; cardiologist; ophthalmologist	Physiotherapy, group therapy		Centrelink (Carer's pension)
Gabby and Brad	Long day care (2 days/wk)			GP; paediatrician	Speech therapy	Counselling	Child protection (older child)
Naomi, Bill and Ingrid		Two disability specific services	Early intervention (therapists and hearing tests)	GP; audiologist; neurologist; paediatrician	Physiotherapy, speech therapy, occupational therapy (OT)		
Kelly, Robert and Jasmine	School	Early intervention		GP	Physiotherapy, OT		
Carrie, Joshua and Hank	Playgroup	Early intervention (1xmnth, 300kms away)		GP (60km away)	OT (60km away)	Respite 4hrs a fortnight (60kms away)	
Shelley, Michael and Gisha	Child care (2x 5hr days/wk)	Two disability specific services	State disability department (case worker – physio and child care aide)	GP; paediatrician; neurologist; ophthalmologist	Physiotherapy; speech therapy; OT chiropractor	Four hours per week in-home respite	
Karen and Rachel		Early intervention		GP; neurologists; cardiologists, paediatrician, feeding clinic	Speech therapy, physiotherapy, OT	Occasional access to a psychologist	
Margaret, Mitchell and Georgia	School	Family disability service		GP; paediatrician; dentist		HACC domestic support (2hrs/wk); occasional respite	
Abbey and Ben	Preschool (3 days/wk)			GP, paediatrician; specialist doctors	Speech therapy; physiotherapy; OT		
Liana, Zach and Ian	Preschool	One disability specific service		Aboriginal Medical Service; paediatrician		Respite (8 hours every 6 weeks)	
Amy and Angus	Preschool (2 days/week)	Early intervention		GP; paediatrician	Physiotherapy, occupational therapy		Child protection (foster carer)

4.2 Service Providers Facilitating and Hindering Family Resilience

The interviews with stakeholders and family members revealed key areas where services providers facilitate and hinder family resilience.

Transitional periods

Transitional periods can be understood as shifts in circumstances. They reflect a point in time characterised by a change in need.

Transitional periods threatening family resilience were a common theme raised by stakeholders. They involve disability-specific transitions (diagnosis and assessment), and transitions that all children face, but that are compounded by disability. These include transitions into school, growth and development (such as puberty), care transitions between family and institutional care and transitions into employment and independent living. Transitions pose particular challenges for children, families and service provision. Their outcomes can have far-reaching and long-term effects on family resilience.

As many of the children are young, the birth and assessment periods were the major transition points that have significantly affected the families interviewed. These periods were very stressful for many of the interviewees. This is a critical time for families to receive appropriate support and therefore essential in supporting families in the resilience process. Therefore service providers play an instrumental role in either supporting families or compounding their stress.

Accessing information and services

Learning about and getting access to appropriate services is an important step in families being able to adjust to having a child with a disability (the first stage of the resilience process).

Most families felt ill-informed about services and supports available to them. Other carers or parents of children with disability were a primary source of information for many families. There was widespread frustration among the families that this information was not provided at the time of the assessment.

Eligibility for and availability of services and supports

Eligibility and assessments for services and supports repeatedly stresses many of the families interviewed, which negatively affects the resilience process. Delays with applications, appeals and rejections place families under considerable stress. They are frustrated by repeatedly having to demonstrate their child’s level of disability and their need for services and supports.

Approval for services is further contentious when families are rejected or placed on long waiting lists because their child is not considered to be high needs enough, yet the families believed they are critical for childhood development or family wellbeing. This is tied to dissatisfaction around the limited availability of services and the reactive nature of service provision, where support often only becomes available when families are in crisis. The availability of services in rural areas was a cause of stress for families and imposed significant financial and time constraints.

Service quality and treatment

The treatment service providers offer - how they relate to families and the quality of service children receive - is critical to effectively supporting families.

Families reported sound relationships with general medical services and were likely to report positive relationships with community supports, such as child care services. Experiences with disability service providers were mixed. Families initially had high expectations of the supports they could receive from specific disability services and where these expectations were met families felt supported, but there was considerable disappointment and exasperation where this was not occurring.

Families were likely to report good practice support as coming from individuals, rather than whole services. ‘Exceptional’ individuals were described as experienced, well trained, effective communicators, who provided consistent and regular follow-up and produced both positive outcomes for the child and the family.

Thus family resilience was supported by some practices and threatened by others.

Service co-ordination

Where it was available and effective, service co-ordination could significantly support family resilience. Only three families experience some level of service co-ordination. However, this made a significant difference to their lives and the lives of their children. Other family members are keen for service co-ordination to be introduced. Co-ordination is important in rural areas to support families and to change the way services work. Stakeholders involved in programs with facilitators noted emotional support as being a key service provided by this model of service provision.

In only one situation did a family have an active case manager who facilitates the range of services the family receives. This is perceived to be an incredibly valuable support and a very important factor in this family’s high level of resilience. All families are adamant about the need for this type of support. They want co-ordinators who were well trained, well informed about the disability sector, and effective communicators who can inform them about the services they can access, offer some emotional support and help co-ordinate the range of supports and services they use.

Holistic support

One of the factors identified by stakeholders and family members that helps facilitate family strengths, and in turn resilience, is holistic support. Holistic supports assist families to actively participate in their community and therefore act as a protective factor in regard to resilience.

Interviewees referred to underlying cultures of practice that either embrace the child within the family and the community, or the child’s disability. Resilience is not served solely by disability-specific interventions, but by strategies that recognise global needs. Respite care that was reliable and trustworthy was highly valued by families interviewed. Families were looking for supports that were positive for their child with a disability, and worthwhile for the family.

Community setting

The issue of community as a vital factor in family resilience was raised by many stakeholders. Coming from a cohesive community was noted as being characteristic of high resilience. Given the benefits of community cohesiveness, a number of stakeholders noted that enhancing this also enhances family resilience. For example, where respite care services are family based and children with disability are exposed to new and different experiences, parents feel supported. Community-mindedness was also raised by a service provider, whose respite service relies on volunteer assistance, as a resource that could be drawn upon to enhance family resilience.

Service provision – facilitating and hindering family resilience:

- Transitional periods are critical periods where a family's resilience may be tested;
- Families reported experiencing most stress and negative experiences with services at the time of their child's birth and/or assessment;
- Learning about and getting access to appropriate services is an important step in families being able to adjust to having a child with a disability;
- Many families experienced difficulty accessing information about appropriate and available services when their child was first born/diagnosed, but also ongoing;
- Families are strengthened by knowledge that their child is getting access to effective services, where some positive outcomes were visible;
- The eligibility process for services repeatedly frustrates families, especially where there are delays with applications, long waiting lists, the need to appeal, or rejections;
- Family resilience is hindered when families are under considerable stress because their child can not get access to a service/support/therapy at a critical time in childhood development, not because they do not need it, but because other children's needs are deemed higher;
- How service providers relate to families and the quality of service a child receives is critical to effectively supporting families;
- Families are predominately content with the service relationships with mainstream health and community services, but are likely to be dissatisfied with some relationships within the disability sector;
- Families feel supported and are strengthened by service providers who are experienced, well trained, resourceful, communicate openly and effectively with the family, and who are willing to find and impart information and provide options;
- The one family that receives co-ordinated support from an effective case manager is one of the very few families who reported not requiring any additional support;
- Co-ordinated support is an important factor that facilitates family resilience;
- All families are adamant about the need for co-ordinated support; and
- Family resilience is supported and strengthened by holistic supports that focus on the family unit.

5 How Services Can Assist Families to Build and Maintain Family Resilience

This section outlines practical support elements for consideration.

5.1 Strengthening families

A whole family approach is critical to strengthening families. Supporting family problem solving, mechanisms to maintain balanced family relationships and recognition of all family members are essential practice elements. Support for siblings is especially important because they often fall out of the sphere of focus. However, despite many policy statements about considering the 'whole' family, stakeholders reported that this often fails in practice. The concerns of family interviewees further reinforce the lack of holistic supports that work with siblings, parents and the family unit.

There are a range of practice elements services could incorporate that may assist families to strengthen, develop or build protective factors (listed below).

Problem solving and communication

- Work with families to identify family strengths;
- Provide tools and resources to assist families to effectively communicate, solve problems and manage behaviour;
- Offer counselling to parents as part of an integrated service;
- Systemic change: service providers may require support to identify tools, train staff and work with families. A working group could consider funding the development of a specific 'resource kit' and training.

Balancing the needs of family members

- Reassure parents about the importance of participating in activities for themselves and provide the support (respite etc) for them to do so (especially important for sole parents);
- Offer holistic supports to assist families and couples to spend quality time together;
- Provide assistance with therapy within the home;
- Provide resources, supports and programs specifically for siblings;
- Increase availability of support for siblings who may be in young caring roles;
- Provide financial and caring support to assist families to meet the needs of all family members.
- Systemic change: funding models could include a specific statement that support will be provided to services to support activities that allows 'family time' of every configuration (family unit; parents as individuals; parents as couples; siblings; child with a disability and siblings; child with a disability as an individual).

Social support and family times

- Sole parents may require assistance to network within their communities;
- Network fathers in similar situations to provide them with some emotional support (systemic change: investigate the viability of an online source of support);
- Service provider and systemic change: eligibility for access to services should not necessarily be based on people's connection to family and friends because even if there are numerous connections they may not be providing tangible support;
- Provide integration assistant support for whole families to participate together in activities they may not otherwise have attended.
- Systemic change: community support groups, organisations and government services need to offer assistance with childcare (perhaps in the form of an integration assistant) to make it possible for children to attend activities and events with their parents.

Future hopes and risks

- Work with families to identify realistic goals and steps to achieve them;
- Forward plan with families for the short-term future – what supports and services need to be accessed or what changes made to make the next twelve months easier?;
- Work with families to identify perceived future risks and strategies to deal with these risks;
- Systemic change: support families so they do not have to leave their rural networks/community to increase service access; or, if families are require to leave, actively support them to settle in new areas through networking and the provision of information;
- Systemic change: provide families with financial support – management, information regarding the list of financial supports they can access, practical support to purchase goods and services their child needs because of their disability, and ensure parents are able to work (if they want to) by adequately supporting their child;
- Systemic change: ensure families are receiving adequate support without older children having to leave school early to fill a substantial caring support role (especially in sole parent families).
- Systemic change: the broad intersections between disability, education and workforce participation need to be recognised as operating for families, as well as the child with a disability. For example, a lack of support for a child with a disability may mean reduced employment of parents and educational attainment of siblings. This relates to a systemic function that requires a long-term approach.

5.2 Strengthening services

Learning about disability: accessing information

- General disability information may be delivered via 'outreach' activities;

- Specific information concerning their child may be best delivered via a 'one-stop-shop' approach, where all relevant services can be accessed through one central point.

Timely access of services and transitions

- Increase the provision of information for families at birth and assessments about their child's disability and services and supports available;
- Systemic change: Base service frameworks on developmental timeframes specific to children: timely, rapid responses are of central concern;
- Systemic change: Train doctors/specialists at 'breaking the news' to families about their child's disability;
- Systemic change: A commitment from governments and service providers that the availability of services would be increased so that children with disabilities would not be competing for limited places and families receive support before they go into crisis.

Effectively delivering support to families

- Where possible maintain consistency with individuals working with families;
- Train staff working for disability services/organisations on how to effectively communication, negotiate and work with families;
- Provide families with negotiating skills to make them feel like they have options and an informed say in the decision making process;
- Systemic change: introduce/improve quality standards for therapists within disability services and working for government departments;
- Systemic change: structure the disability support system to assist services to provide life course support for families;
- Systemic change: support co-ordinators or facilitators to be mobile so that they can stay with families irrespective of changes in families' lives.

Service flexibility

- Offer flexible funding arrangements that may be directed toward the child and/or the family unit or other family members;
- Base service provision on priorities families identify; that is, families drive the service planning process.
- Systemic change: Introduce/increase flexible funding models that can be individually tailored to the family as a whole, the child, parents, other carers, such as grandparents, and/or siblings;
- Systemic change: focus further research on how funding models can achieve and sustain flexibility and responsiveness to families' changing needs.

Co-ordinated Support: The Facilitator Model

- A facilitator was given as a possible solution to many of the issues stakeholders and family members raised in this study.

- Families were especially eager for their access to services, supports and information to be co-ordinated.

Facilitator models were popular because they:

- Minimise the requirement for families to repeatedly demonstrate their eligibility;
- Assist families to navigate the complex and confusing disability landscape;
- Allow parents to be parents, not case managers or service coordinators;
- Provide families with information regarding their entitlements and offer emotional support.

The ideal facilitator model would have the following qualities:

- Committed to an early intervention approach;
- Well trained and well informed about the disability sector;
- Assigned at the time of diagnosis/assessment;
- Co-ordinates services to the child and family over the long-term;
- Improves co-ordination between services;
- Effective communicator who provides families with information, emotional support and helps facilitate trust with other service providers, such as volunteers or respite carers;
- Social work or psychology trained, as their perspective is broad.

5.3 Governance issues

From a governance perspective, it is important that future development of facilitator and other service provision models also consider:

- How disability interventions interact with other interventions and family circumstances and for what outcome for all family members;
- Inclusive practices into mainstream life;
- Achieving consistency of support across all domains of a child's life – home, school, community life, and 'fun stuff';
- How interventions operate across all domains;
- How policies and practices to 'do things smarter' with current resources;
- People from different demographic backgrounds, such as indigenous, sole parent and rural/remote families have particular needs that may require further address.

6 Conclusion

Family resilience is a process that includes three steps: crisis/adversity; drawing on strengths and resources to adjust; and adapting and resuming family functioning. The interviews (with eleven families and thirteen key stakeholders) reinforced that family resilience operates on a continuum that shifts and changes over time and is a process that families can repeatedly experience, often as a direct or indirect result of their child's disability.

The research found numerous protective and risk factors that families face in negotiating the resilience process. Having resources and strengths to draw on is critical for families to experience resilience. Most families have internal strategies they use to endure difficult periods or to solve problems; however accessing formal and informal supports also protects families. While the research found the majority of families receive informal emotional and/or practical support, almost two-thirds of the families reported that they do not get support when they most need it.

Service provision can also facilitate and/or hinder family resilience depending on its availability, accessibility and quality. Numerous characteristics of service provision (especially receiving access to effective, high quality services at appropriate periods of time) were found to support family resilience. Some families were dissatisfied and feel unsupported by the disability sector. Disability providers, however, who are experienced, well trained, resourceful, willing to find and impart information, communicate openly and effectively with the family and provided options, help families in the resilience process. The co-ordination of supports and services that are holistic - that embrace the child within the family within the community – are also important factors in the resilience process.

There are numerous practice elements services can implement, develop or expand that work to improve services, strengthen families and help facilitate family resilience. For example, offer holistic support to assist whole families, not just the child with a disability and work with families to plan for the future – both achieving goals and combating risks. There is overwhelming support among families and stakeholders for the facilitator model. Families where a young child has a disability can be supported through the resilience process if service providers assist families to build protective factors, plan for the future and counter risks; and if effective resources are available through holistic, flexible, accessible and high quality service provision.