Family resilience where families have a child (0-8 years) with a disability: literature review

Author:
Muir, Kristy

CHILDREN AND YOUNG PEOPLE
WITH DISABILITIES (INCORPORATING
CHALLENGING BEHAVIOUR)

FAMILY RESILIENCE WHERE FAMILIES HAVE A CHILD (0 - 8 YEARS) WITH A DISABILITY: LITERATURE REVIEW

Report Prepared for the Disability Policy
and Research Working Group

Research team

Social Policy Research Centre, University of New South Wales

Kristy Muir and Jacqueline Tudball

Disability Studies and Research Institute

Sally Robinson and Edwina Pickering

Advisory team

Social Policy Research Centre, University of New South Wales

Ilan Katz and Karen Fisher

Author

Kristy Muir

Contact for follow up

Dr Kristy Muir, Senior Research Fellow and Evaluation Manager, Social Policy Research Centre, ph 02 9385 7818 email k.muir@unsw.edu.au

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1 Introduction

1.1 Background

In September 2006 the Disability Policy and Research Working Group, the key representative body for government agencies in the Commonwealth, States and Territories, engaged the Social Policy Research Centre (SPRC) at the University of New South Wales (UNSW) 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.

1.2 Methodology

A qualitative methodology is being used to develop an understanding of family resilience in families who have a child aged 0 - 8 years with a disability. The research is being 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.

For the literature review and data collection, 'family' will be based on a range of combinations of people who have a child 0 - 8 years with a disability. Family types, for example, include sole-parent, step, blended, gay, extended, couple, nuclear and dual and grandparent care (Gilding 2001:8-10). Families with children 0 - 8 years of age will be interviewed, but there is nominal literature available on families where the child with the disability falls into this precise age group. Therefore literature drawn upon primarily covers families with pre-school aged and primary school aged children. To fill gaps in understanding family resilience where a child has a disability, this report also includes some literature on children up to 18 years of age.

This report reviews and analyses recent Australian and international literature from a variety of disciplines. It builds on the work of Own et al. (2002) and the Nucleus Group (2002) by examining cross-disciplinary research. Published and unpublished material was consulted in the areas of disability; child, adult and family resilience; social work; psychology; social policy; public health and medicine; education; history and family studies. Authors include academics, government personnel and service providers.

1.3 Literature review

This report is divided into three sections. The first part defines, describes and identifies family resilience as it applies to families where a child (0 - 8 years) has a disability. To contextualise resilience, this report traces the shift from studies on childhood to family resilience.

The second part of the report looks at how this understanding of family resilience can be integrated with service provision. It looks at the affect service providers and professionals can have on families and the challenges of implementing family resilience research into practice. It provides 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. These practice elements can be applied to different service models and supports that families depend on. Therefore, the report does not compare an exhaustive list of services, but rather focuses on the key factor to good practice – service co-ordination – and provides a few examples of existing services that have been evaluated.

The third part of this report explores the practicalities of measuring family resilience where a family includes a child with a disability (0 - 8 years). It looks at the challenges, problems and limitations for practitioners when attempting to measure family resilience and the reliability of these tools. This includes providing examples of researchers and service providers who have developed, used and evaluated family resilience measurement tools. Finally, this section offers ideas of how service provision can move forward in regard to working with families on resilience.

1.4   The effects of childhood disability on families

All families, regardless of whether the family includes a child with a disability, often have positive experiences and face challenges and demands. Similarly, parents who have a child with a disability report feelings of love, happiness and hope, but also challenges (Dobson et al. 2001; Kearney and Griffin 2001; Marsh 2003). Some families where a child has a disability experience additional demands and are more likely to experience increased risk and vulnerability than other families. Without adequate supports and services, these families can experience significant stress. The process of resilience – how families meet these stressful circumstances – is relevant to all families, especially where a child has a disability.

As will become evident in Section 2, resilience is only applicable to individuals and families if they have been exposed to an event or situation they perceived as unusually stressful or traumatic. It is important to understand the stressful circumstances some families who have a child with a disability can experience. A child with a disability may require more parental assistance and supervision within and outside the home, than a child who does not have a disability (Bain 1998:599; Dobson et al. 2001; Roberts and Lawton 2000). Families with children with challenging behaviours may experience compounded levels of stress (Bain 1998). The extra demands of parenting a child with a disability can affect parents' objectives and their working, social and home lives (Dowling and Dolan 2001:21). For example, mothers are less likely to work and fathers have been found to decrease their working hours. This can affect their job opportunities, aspirations and promotions (Bain 1998; Dobson et al. 2001:32).

Workforce sacrifices can significantly affect a family's income. Consequently, parents of children with a disability tend to have lower than average incomes (Dobson et al. 2001; Lukemeyer et al. 2000). This is further compounded by the additional costs of raising a child with a disability (Lukemeyer et al. 2000). Dobson et al. (1998; 2001) found that it costs between two and three times more to raise a child with a disability than a child without a disability; and this only included 'minimum essential costs'.

To meet the expense of having a child with a disability, parents spend less in other areas, such as on themselves, leisure activities and holidays. Despite these savings in other areas

(in the United Kingdom and Canada, where budget expenditure research has been completed), the majority of parents involved in the research reported being unable to meet the financial expenses deemed to be essential for their child with a disability. Parents could not afford half the goods and services they deemed 'essential to achieve a reasonable quality of life' for their child with a disability. Parents whose children were five years or younger had the largest gap between the amount of money they had to spend and what was required (Dobson et al. 2001). Canadian research on families with school-aged children with a disability produced similar findings; the majority of families interviewed reported being unable to afford aides, support for activities or modifications to the home needed for their child (Fawcett et al. 2004).

Social isolation is a further problem experienced by some families with a child with a disability because of financial, time and respite limitations, as well as a loss of previous social networks and stigma (Bain 1998; Dobson et al. 2001:26-7; Patterson 2002:356). These social, working, financial and other stressful situations can affect family members' mental health. Parents who have a child with a disability are likely to experience more stress, lower levels of marital satisfaction, poorer mental health and lower levels of well-being than other families (Gardner and Harmon 2002:61; Patterson 2002:356).

Other family members' lives may also be affected. If support is inadequate, parents may have less time and energy for other family members and siblings may be expected to share some of the caring responsibilities (Bain 1998).

A number of families have difficulty coping with these stressful circumstances. Parents with a child with a disability are more likely to be divorced or separate than those who have children without a disability (Mauldon 1992). A 1996 survey of 171 NSW based families with a child under 7 years with a disability found one in four of these families had 'either sought alternative residential care for their child or considered it might become necessary'. For those who had already sought care, 'family survival – physically socially and emotionally – was at stake' (Bain 1998).

Therefore, while parents who have a child with a disability report positive experiences and feelings of love, happiness and hope (Dobson et al. 2001; Kearney and Griffin 2001; Marsh 2003), without adequate supports and services, some of these families may also experience significant stress. This report explores the process of resilience to understand how families with a child with a disability deal with these stressful circumstances.

2 Defining, describing and identifying family resilience relating to families who have a child with a disability aged 0 - 8 years of age

This part of the report defines, describes and identifies family resilience as it applies to families where a child (0 - 8 years) has a disability. The study of resilience began in the 1970s with a focus on children. This section will trace resilience studies from children to families. Understanding family resilience goes beyond the individual to understand the group's ability to function successfully in or after difficult periods. Although there are some differences in the resilience process, the definition of family resilience is applicable to both families who have a child with a disability and those who do not.

2.1 Background of resilience studies

The study of resilience emerged in the early 1970s (Masten 1997). Currently, resilience is seen as having the ability to function effectively or positively 'in adverse circumstances' (Masten in Schoon, 2006: 7). It was, and still is, predominantly studied in relation to disadvantaged children (Guralnick 2000; Schoon 2006) in terms of trying to understand why some children who have experienced adversity fare well, while others do not.

Childhood resilience is about 'the process of', 'capacity for' and/or 'outcome of' children successfully adapting 'despite challenging or threatening circumstances' (Masten, Best and Garmezy in Howard et al. 1999). The literature bases childhood resilience on a complex interaction between parenting factors, a stable and safe home environment, and an influential adult outside of the home (McCubbin et al. 1997:3-4). Therefore as an individual's resilience – their ability to cope with stressful situations – is formed during childhood (Bartley 2006:8,16), arguably it may be challenging to assist adults through the resilience process in the family structure.

Compared to childhood resilience, little is understood about resilience in adulthood (Bartley 2006:12). Two major factors that have been found to help build resilience in adults are paid work and a united family, which are more likely to increase satisfaction, well-being, health and social networks. Family-friendly work practices may also assist, along with easy access to child and health care and active participation in social networks.

Factors that may place an adult at risk of low levels of resilience are sole-parenting, divorce and unemployment. These situations can place adults at risk of increased distress, less effective parenting skills, separation and divorce, economic stress, low income and poor housing conditions (Bartley 2006:12-13). While divorce is a risk factor, separated or divorced families can experience resilience. Greeff and Merwe (2004:59) found that support from family and friends, open communication with family, work and financial security promoted resilience in divorced families. Silberg (2001:57) found co-parenting practices could also protect sole-parents from poor outcomes.

Although resilience is primarily applied to individuals (and mostly children, rather than adults), much of the resilience literature is based within Bronfenbrenner's Ecological Model (1979), which acknowledges the role of families and communities in promoting

resilience: resilience is based on individual characteristics, the family environment, the community a person lives in and their access to and experiences with services and supports (Schoon 2006:1-2). Importantly, family functioning and family resilience plays an instrumental role in a child's developmental outcomes 'regardless of … disability status' (Crnic and Stormshak 2000:209,211).

2.2   Defining family resilience

> Families can and often are overwhelmed and challenged severely in the face of adversity, and they do stumble, experience disharmony and imbalance, and sometimes even deteriorate in the face of a family trauma. These family crises are often successfully negotiated by the family using its own resources, capabilities, and recovery factors. Families do bounce back and adapt to the situation by changing their patterns of functioning and changing the aversive condition that has placed or maintains the family system in its current problematic predicament (McCubbin et al. 1997:6).

Derived from McCubbin et al.'s (1997) definition are three interrelated steps or conditions that form the basis of family resilience:

1. The family faces adversity – a perceived 'misfortune, trauma [or a] transitional event';

2. They draw on their strengths and resources (including services) to try and maintain their normal patterns of functioning, which McCubbin et al. (1997:5) refers to as 'adjustment'; and

3. They 'bounce back', recovering from the adversity, despite having to make some changes, or 'adaptations', to the way the family functions (McCubbin et al. 1997:5)

Therefore the process of how families *adapt* is an important part of family resilience.

In addition to the three conditions above, Patterson (2002:350) maintains that families require an outcome they are capable of achieving, and to identify potential risks that can interfere with the family will achieving the outcome.

According to researchers such as McCubbin et al. (1997), Patterson (2002), and Coleman and Ganong (2002:101), experiencing resilience does not require families to emerge from adversity stronger than prior to the trauma or stressful event. However other family resilience researchers argue that to experience resilience families not only have to survive the event, but 'emerge from the situation feeling strengthened, more resourceful, and more confident than its prior state' (Simon et al. 2005:427). As a family's resilience sits on a continuum – rather than being a dichotomy of 'resilient' or 'dysfunctional' – and since it can change over time, this report uses the former definition - that to experience resilience a family does not have to be stronger after recovery than they were prior to the stressful event.

As the step-wise nature of the three conditions suggests, family resilience is a process, not just an outcome. As (De Haan et al. 2002:276) point out: 'family resilience describes

the path a family follows'. Patterson also reinforces the importance of understanding family resilience as a 'process and not a trait'. She recommends researchers and practitioners take on the psychologist's perspective of distinguishing between 'resiliency' as a trait and 'resilience' as a process (2002:352, 354). Throughout this report 'family resilience' is predominantly used because it emphasises two key components: the *process* of how families with a child with a disability *adapt*.

2.3 Defining and describing family resilience where the family includes a child with a disability

The three conditions that define family resilience (outlined in Section 2.2) are relevant to families whether they have a child with a disability or not. The first condition - exposure to a stressful event or transition – is likely to be applicable for families who have a child with a disability, but it also depends on how families perceive situations. That is, if parents do not perceive their child's disability (or another situation) as stressful or traumatic, then they do not fit within the definition of resilience (Peterson and Hawley 1998:221). However, given the effects of a child with a disability on many families (described in Section 1.4), it can be assumed that almost all families living with a child who has a disability resulting in high and/or complex needs meet the first criteria.

The second condition – that families have resources and strengths to draw on to help them maintain some level of functioning while dealing with the event or stress – means that only families with resources and strengths to draw upon can be expected to have the capacity for resilience. Therefore, in supporting a family to strengthen their resilience, fundamental supports need to be in place. Assisting families to build a foundation of resources (such as financial support, the provision of adequate housing, access to appropriate services) and strengths (like parental behaviour management and problem solving skills) is the first fundamental step.

The third criterion – the ability to adapt – is equally applicable to families with or without a child with a disability. Families experience resilience if the first two criteria are met and then they make necessary changes to resume family functioning (even though the way the family functions may have changed).

Gardner and Harmon (2002:62) defined resilience in families where a child has a disability consistent with the three tiered process outlined above, but added that these families can also 'balance the needs of other family members with the needs of the child [with a disability, and] … negotiate constructively with service providers'. They went on to describe a family with resilience as having 'a positive attitude to family circumstances' and 'a willingness to take opportunities for rest, recreation and celebration'. While the inclusion of 'a willingness to take opportunities for rest, recreation and celebration' may assist the process of family resilience, it does mot necessarily underpin it. Thus, it may not assist in trying to narrow down a broad definition of family resilience. That is, for a family with a child with a disability, a family's willingness for these activities may be related to their strengths, but can also be restricted by whether they have the 'opportunity' – in terms of access and resources, such as money, time, leave, respite care and other services. This may be difficult for many families when families with children with disabilities are likely to earn less than the average wage, have increased expenditure

to support their child's needs and little or no access to respite and have full-time caring responsibilities and the associated shortcomings, including interrupted sleep.

Gardner and Harmon's (2002) first point about a family's ability to 'balance the needs of other family members with the needs of the child', however, is important for understanding the nature of family resilience. While there has been little research on the resilience of siblings who live with a brother or sister with a chronic disability (Bellin and Kovacs 2006:209), they are more likely to have emotional, behavioural and social problems than their counterparts (Bellin and Kovacs 2006:211).

In short, family resilience where the family includes a child with a disability is a process very similar to general family resilience as described by the three steps. However, for a family with a child with a disability, the adversity, resources/strengths and adaptability are situation-specific. These are described more fully below.

Step 1: The crisis, event or trauma

The family experiences one or multiple situations they perceive as *adverse*. This may relate to the disability, especially in periods of transition, such as diagnosis, assessment and school entry, but not necessarily exclusively. The trauma could be in relation to other family issues, such as illness or separation. Importantly, the adversity is such that the family is at risk. At the time of the crisis, trauma or stressful transitional event families often experience 'disorganisation, conflict, confusion [and] resentment' (De Haan et al. 2002:277).

Step 2: Using resources and strengths or 'protective factors' to adjust

The family has some *resources* and *strengths* to draw on while trying to adjust to the difficult situation. This stage includes having an outcome that the family can achieve. Family members start to adjust by drawing on supports, resources and strengths from within and outside the family (De Haan et al. 2002:277; Patterson 2002:356). These are discussed in further detail in Section 2.4.

Step 3: Reorganisation and recovery

The final step in family resilience is for families to *adapt* the way their family functions and recover from the crisis or event, despite the presence of risks that interfere with the family's ability to. Although the family may have changed the way it functions, patterns of functioning are resumed and the family is able to balance the needs of other family members with the need of the child with a disability.

However, families will recover with varying levels of resilience, emphasising how family resilience is not a trait, static or absolute. Instead, it is a process that will change over time, exist on a continuum of levels and is dependent on numerous factors. The most important of these factors are seen as the resources and strengths.

2.4   Resources and strengths – protective and recovery factors

To understand how families resume functioning after experiencing a traumatic event or stressful transitional situation (family resilience), McCubbin et al. maintain that it is

important to look at family protective and recovery factors (McCubbin et al. 1997:4). This 'protective and recovery' framework comes from the psychology discipline and is based on the 'family stress and coping paradigm' (McCubbin et al. 1997:4; Skinner and Edge 2003).

Protective factors can be both tangible and emotional. The former includes resources like support networks, financial capital and access to social support, services and adequate information. The latter encompasses a person's strengths, such as their psychological capacity to deal with situations (Hudson et al. 2003:238; Speedwell et al. 2003:219; Woolfson 2004:1). This report uses this psychosocial perspective to understand the extent and nature of the resilience of families who have a young child with a disability.

Protective factors

Protective factors can come from within the family or the community. Contemporary research highlights the influence of social, economic and emotional factors in determining a person's or family's resilience. Family, friends, peers and neighbours and the institutions and resources accessed in the community are essential to protect families, but a parent's self-efficacy – the way they perceive their parenting skills, such as behaviour management – is also important. The more self-efficacy a person has the less likelihood they will be emotionally distressed in adverse situations (Hastings and Brown 2002: 222)(Schoon 2006:1-2).

Based on extensive research on families, McCubbin et al. highlight key factors that protect families of all types and help them recover, or experience resilience. These are listed in Table 1. While all factors are important for families with a child with a disability, the Table is presented according to the factors that are most applicable to families who have young children and where a child has a disability. Four factors were found to be critical across all family types (in general, where children are young and where a child has a disability). These four factors include the ability to solve problems and balance relationships within the family, family hardiness, social support and routines.

Problem solving and balancing family relationships involves being able to meet the needs of all family members, not only the child with the disability. It also includes managing interpersonal relationships within the family so that tensions and conflicts can be solved (Gardner and Harmon 2002; McCubbin et al. 1997; Parker 2001:82; Patterson 2002).[1] The relationships between family members are likely to be affected by each individual's temperament (the way a person reacts and responds) and how family members with different temperaments interact (Smart and Sanson 2001:11). How 'difficult' parents find their relationships with their children will depend on their own temperament, as well as social and cultural factors. For families who have a child with challenging behaviour, the

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[1]   Parker also points out that coupled with an 'ability to resolve conflict', marriages or partnerships are protected by minimal criticism and positive traits outweighing negative ones at a 5:1 ratio (Parker 2001: 81-89).

role of temperament and early intervention is especially important in assisting families to manage tensions and solve problems within the home (Smart and Sanson 2001:15).

The second protective factor is having a durable family that works together in difficult times and believes that the family will remain together despite the problems faced. Thirdly, 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. Adequate social supports have also been found to improve parenting practices (Peterson and Hawley 1998:222). Social supports include participating in social and recreational activities in the community, both as individuals and together as a family (Gardner and Harmon 2002; McCubbin et al. 1997; Morison et al. 2003; Patterson 2002). Accessing government and community supports and having effective relationships with professionals is a further component of this protective factor (Bartley 2006:4-5; McCubbin et al. 1997; Patterson 2002:357). The fourth critical protective factor is having routines, such as meals together, bedtime and other rituals, and spending time together to acknowledge and celebrate special occasions, such as birthdays, religious events or family traditions (McCubbin et al. 1997; Patterson 2002).

The next two factors listed within the table – hope and flexibility – are also very important for families with young children where a child has a disability. Hope is essential in regard to building and strengthening family resilience (McCubbin et al. 1997; Morison et al. 2003:129; Patterson 2002). The nature of what families hope for or the goals they have is not important; what is important is that the desire or goal can be achieved. In regard to a child with a disability, therefore, hope can range from 'hope for a cure, to hope for adequate care and treatment' (Morison et al. 2003:129). Hope may need to be 'reframed' over time as other transitions and events occur (Morison et al. 2003:129). Flexibility is important. The capacity to be flexible will also assist families to adjust and adapt to stressful events and change their functioning and routines accordingly (McCubbin et al. 1997; Parker 2001; Patterson 2002).

While financial management was not specifically mentioned by researchers examining family resilience where a child has a disability, McCubbin et al. (1997) included it as crucial for a family with young children. Further, given the financial stress many families with a child with a disability experience (Section 1.4), financial management and perceiving the families' financial situation as adequate to meet the families' needs should be recognised as an important factor for families who have a child with a disability.

The next three factors reiterated by researchers (e.g. (Gardner and Harmon 2002; Morison et al. 2003; Parker 2001) in relation to both general family resilience and resilience specific to families where a child has a disability are truthfulness (transparency and open communication about the disability between families and professionals and within families), empowerment (of both partners in terms of their relationship and their relationship with service providers) and spirituality or meaning (finding meaning in the crisis or being able to make some sense of the situation).

The final general factor McCubbin et al. (1997) cited as important for families was the health of the family members. While this was not listed as an important protective factor for families with young children or where a child has a disability, it should be considered where families with young children with a disability are concerned. 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.

Table 1: Key protective factors for family resilience where a family has a child (0 - 8 years) with a disability

Key protective factors[1]	Description[2]
Family problem solving and balanced relationships	Families have effective communication, which enables then to solve problems. Where families have young children it is especially important to have 'balanced interrelationships among family members' so that the needs of all family members, including siblings, are met and the family can 'resolve conflicts and reduce chronic strain'.
Family hardiness	The family works together to face challenges, feels they have some control over their lives and are confident that the family will remain together despite the adversities faced.
Social support (practical and emotional)	Having and maintaining positive relationships with a network of people who can provide a range of practical and emotional supports. This includes making time to maintain social relationships and activities, such as recreation (family based and individual). It also involves effectively drawing on community and government support from service providers and getting access to practical, physical resources along with having knowledge and skills in relation to the disability.
Family time and routines	Maintaining predictable and stable routines, such as meals together and bedtime rituals. When families are in crisis it helps if some rituals can be maintained because of the stability they create. Acknowledging and celebrating special occasions, such as birthdays, religious events or family traditions, is also important.
Hope	This is 'vital' to resilience and at the core of a family adapting to a situation. It is not important what the family hopes for, but their 'wishes or desires' need to be 'accompanied by a confident expectation' that these hopes can occur.
Flexibility	Families are prepared to change patterns of functioning to a range of areas, such as rules, roles, meanings and/or lifestyles.
Financial management*	Families are able to manage money effectively and feel satisfied with their economic situation.
Truthfulness	Families are informed with the facts and family members are truthful with each other. This is important between service providers and families and within families (between both parents and between parents and siblings).
Equality and empowerment	Both partners are empowered.
Spirituality/ meaning	Families are able to make sense of the crisis/event/situation.
Health	If family members are not healthy the family system can become unstable.

Sources and notes: 1. (McCubbin et al. 1997)
2. (Gardner and Harmon 2002; McCubbin et al. 1997; Morison et al. 2003:129; Owen et al. 2002; Parker 2001; Patterson 2002)
*This was not one of McCubbin et al.'s (1997) ten general family resilience criteria, but was included in

McCubbin et al.'s protective factors for families with young children and school-aged children.

A family who experiences resilience will draw on some of these protective factors to assist them through the crisis, adjustment and adaptation stages. A combination of factors may be used to protect, strengthen or assist families. Not all factors need to be present for a family to experience resilience. Orthner et al. (2004:159-167), for example, found that low-income families with high levels of resilience were protected by other factors within the list, such as communication and problem solving skills and access to and use of social supports. As families change over time, factors that may have been protective for them at one point may become risk factors later and strategies that help one family, might not work for another (Coleman and Ganong 2002; De Haan et al. 2002; McCubbin et al. 1997; Patterson 2002).

Therefore measuring resilience cannot simply rely on a list of protective factors. Such a list may also underrate or dismiss factors that are important for families at different stages, of different cultural backgrounds or living in varying geographic locations. For example, families with preschool and school-age children might find religious programs in the community, other community based supports and a sense of belonging within a community to be important protective factors, but these might decrease as children get older and will be less important depending on a family's religious beliefs, their values and other social support networks (McCubbin et al. 1997:6).

Risks

If protective factors are absent, families can be at risk of being unable to adapt and adjust. Risk factors include the antitheses of the protective factors within Table 1: an inability to manage relationships between family members or meet needs of each of the family members; a lack of durability, or belief that the family will not survive; limited or no social supports; disorganised functioning and lack of celebration; a loss of hope and pessimism about the future; inflexibility; financial stress; a lack of transparency in sharing information; feelings of disempowerment and helplessness; and/or an inability to find meaning or make sense of difficult situations can place a family at risk.

Multiple and compounding stressful situations can also place families at risk (Bartley 2006:5). The correlation between compounded stress over time and poor family functioning has been found for mothers who have a child with a disability (Peterson and Hawley 1998:221). Even before years of accumulated stress relating to a child's disability, birth can be an incredibly stressful event that a couple may have difficulty coping with, particularly if they have experienced previous problems. Where families have three or more major stressful situations prior to the birth of a child, they are particularly vulnerable to poor outcomes (Peterson and Hawley 1998:225). Two common types of stress experienced by families are economic and social (Peterson and Hawley 1998:221). Families under financial stress are more likely to experience depression, relationship problems, poor functioning and are likely to have low levels of resilience and therefore difficulty adjusting, adapting and recovering from stressful transitions or events (Bartley 2006:5; Patterson 2002:354; Peterson and Hawley 1998:222).

2.5 Identifying family resilience

Defining and describing family resilience is easier than identifying it. Gardner and Harmon (2002:62) identified 'the phenomenon of resilience' in six families who have a child with a disability (18 years or younger). The mothers of six children with high support needs were interviewed (these women were also in 'long-term relationships' and their child had been diagnosed with a disability more than five years earlier).

Gardner and Harmon identified attributes they believed rendered resilience in these women. They had a well-developed 'sense of self', 'accept[ed] the reality of their child's disability', they had access to social and emotional support, were satisfied with their marriages, worked with their partner to solve problems, felt empowered regarding decision making, were optimistic and provided time for themselves and other family members (2002:62-67). While Gardner and Harmon may have found six women experiencing resilience, it is difficult to conclude that they had identified family resilience because only the mothers were interviewed. The interviews were also carried out at only one time and therefore the shifting nature of resilience levels was not captured. For this reason, Carpenter warns practitioners and professionals against getting families to 'accept' their child's disability because at each stage of life 'the reality … of having a child with disabilities is constantly renewed' (Carpenter 2000:138).

Gardner and Harmon's case studies may also be exceptional, rather than reflect the general perceptions and experiences of mothers who have a child with a disability. As Gardner and Harmon recognise, the women interviewed 'had resources available to them, such as finance, education and respite' (2002:68). These three resources are critical to the attitudes, perceptions and behaviours of the women interviewed. Their resilience is not constructed within the family as solely a psychological phenomenon. The 'phenomenon of resilience' Gardner and Harmon talk about is a complex interaction between tangible resources and psychological processes or strengths. The research also offers little in regard to identifying resilience families where a young child has a disability (as the children in the study had been diagnosed with a disability at least five years prior to the interview).

Patterson did not strictly define families who experience resilience. She maintained they only required one of four conditions: 'family formation' (a sense of belonging, identity and/or meaning); 'economic support' (shelter, food, clothing and other needs for development are met), 'nurturance, education and socialization' (family provides 'physical, psychological social and spiritual development'); and protection of vulnerable members (2002:353). For families where a child has a disability, the fourth area was not necessarily considered enough to gauge resilience in the family. If families are focussing on the child with the disability at the expense of other family members, the third criteria may not be met for the child's sibling(s) (Patterson 2002:353).

2.6 Conclusion

Family resilience where the family includes a child with a disability is a process that can be defined by adversity, resources/strengths and adaptability. Firstly, families experience one or multiple situations of *adversity* (this may or may not be related to the child's

disability, but is likely to occur during periods of transition) that places the family at risk. Secondly, families draw on *resources* (for example, private and public social, emotional and financial resources) and *strengths* (such as, their psychological capacity to cope and build or reframe hope) to adjust to the adversity. This involves having an outcome that the family can achieve. And thirdly, the family recovers from the event or situation by *adapting* family functioning, even though there was a risk that the family may not have adapted. The resilience process concludes with families resuming a pattern of functioning and balancing the needs of other family members with the need of the child with a disability. Family resilience is a process that will change over time and can exist on a continuum of levels. It involves the interaction of a number of key protective and risk factors. Defining and describing family resilience is less complex than identifying how service providers can most effectively support families through the resilience process. This is the focus of the next part of the report.

3 Service models and family resilience

> The key to giving young people a good start in life is to help their parents (Bartley 2006:5).

This part of the report examines how the study of family resilience where a family has a young child with a disability can be integrated with service provision. It looks at 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 is provided. These practice elements cross service models and, as families depend on a range of supports, best practice is related more to co-ordination than a definitive service. Therefore this part of the report does not compare an exhaustive list of services, but provides a few examples of existing services that have been evaluated.

3.1 The affect of service providers on families

Services and professionals can assist families to build or maintain resilience, but they may also negatively affect families. Effective, intensive support services have been found to be 'supportive through stressful periods and prevent family breakdown' (NSW Ombudsman 2006:6). However poor service delivery, difficulty accessing services, conflict with professionals and other service related problems can place added pressure on families who are already under stress (NSW Ombudsman 2006:i; Patterson 2002:356), and such problems are frequently cited. The NSW Ombudsman reported that it is not clear how, where or when families can access intensive supports when they are at risk of breakdown and the Ombudsman found that people of culturally and linguistically diverse backgrounds may have more difficulty accessing services (NSW Ombudsman 2006:6). Carpenter (2000:135) concluded that despite extensive research and consultations with families, services are still not meeting their needs. Bain (1998:599) pointed out that while services justly target the right of the child 'to live in the least restrictive environment', they do not always recognise the rights of other family members through the provision of adequate and appropriate support.

3.2 Implementing family resilience research into practice

It is difficult to move from 'family resilience' as defined and described in research to implementing it into clinical or family practice (Patterson 2002:349). Practitioners working from a family strengths perspective will usually identify the family's strengths, rather than just focus on the deficits and are often working with families during the crisis and early in the readjustment period. Researchers often focus on the process of resilience once an outcome has been reached (that is, after the risky or very stressful situation). For practitioners working with families on resilience there are a number of practical problems – understanding resilience as a process and not a trait; determining whether a situation is risky or sufficiently stressful to test a family's resilience; assessing resilience in families (measuring family, rather than individual, resilience); and understanding and identifying the factors that protect a family and how these factors are used by families in the resilience process (Patterson 2002:349).

Patterson (2002) attempted to connect family resilience research and practice by using family stress and coping theory and the Family Adjustment and Adaptation Response Model. Practitioners use this model to asses how families 'balance *family demands*' (such as stressful events and family tensions) with '*family capabilities*' (the resources the family has access to and what the family does to cope), and how they 'interact with *family meanings*' (how family members perceive situations, their family in general and in relation to others) to achieve 'a level of *family adjustment* or *adaptation*' (Patterson 2002:350-1). For example, a child is diagnosed with a disability (demand); the parents have educational and financial resources to become informed, advocate for the child and provide aides to assist the child (capabilities); the family makes some sense of what has occurred (meaning) and the family's routines and social/home/work functioning are restored or adapted (family adjustment or adaptation). When the demands outweigh the family's capabilities the family is likely to experience crisis (Patterson 2002:355). This see-saw model offers practitioners a practical approach to understand how family resources and strengths can assist to counter difficult situations. It does not, however, provide an explanation specifically of how existing service providers can work with families to build and maintain their capabilities and adjust family functioning to recover from a crisis.

3.3   Getting the conditions right for building or maintaining family resilience

If an objective of service models is to strengthen or build family resilience, the foundations for resilience must be set for practitioners to assist families. One of the criteria for families to experience resilience is that they have resources and strengths to draw from. As mentioned earlier, these resources and strengths come from within individuals, families and communities and from the services and supports available and accessed at local, state and national levels (Bronfenbrenner 1979).

For a family to experience resilience, sufficient social and financial support, such as adequate housing, decent, well resourced social services and access to training, employment, health and child care, are required (Peterson and Hawley 1998; Scott 2001:76). Peterson and Hawley (1998:226) advocate that if these aspects of a family's life can be addressed, the 'social context' of the family will improve and stress will be reduced, which in turn will assist to improve family functioning. Patterson (2002:359) similarly argues that 'the absence of needed community resources to support families in fulfilling their core functions … undermines family resilience'. A further component of establishing the right conditions for strengthening families is ensuring enough services are provided (Bartley 2006:22; Patterson 2002:359).

Once these foundations are set, focus can shift to how and when services are best provided to support family resilience. Timing needs to purposeful and effective. Research has found that the earlier, longer and more sustainable the intervention the more effective it can be for families (Bartley 2006:9). Parents with a child with a disability have reported the time of diagnosis as the time when intensive support tailored to individual need was particularly required (Dobson et al. 2001:25).

Prevention and early intervention frameworks can assist families to increase their resources and strengths to cope, so that stress does not compound and they are supported

through difficult periods like transitions before crises occur. Services can do this by assisting families to strengthen the protective factors.

3.4 Strengthening resilience by providing families with the opportunity to maintain and/or build protective factors – a descriptive framework

Table 2 includes a list of practice elements service providers and professionals currently use or could use to assist families to build, maintain and strengthen a family's protective factors. The framework applies the eleven key factors identified in Section 2.4 as important for family resilience.

Table 2: Descriptive framework of practice elements to build, maintain and strengthen a family's protective factors

Key protective factors for families	Examples of practice elements
Family problem solving and balanced relationships	• Communication and problem solving skill training; • Parenting programs to assist with family based problems and interpersonal relationship conflicts; • Behaviour management courses; • Financial and caring support to assist families to meet the needs of all family members; and • Specific resources/supports/programs for siblings. (Bellin and Kovacs 2006:213; Gardner and Harmon 2002; Hastings and Brown 2002; McCubbin et al. 1997; Parker 2001:82; Patterson 2002; Smart and Sanson 2001)
Family hardiness	• Skill development for families to work together; • Assist parents to feel in control of situations; and • Help families to maintain or build confidence that the family will stay together.
Social support	*Social networks – family and friends* • Provide financial support to ensure extra expenses of having a child with a disability are covered so families do not have to sacrifice social and recreational activities; • Provide sufficient hours of respite care so that parents have the time to remain connected to friends and social and community activities; and • Provide supports that link families together. *Public and community support* • Provide adequate services to support families where a child has a disability; • Inform families about what supports are available and how to access community and government supports; • Link families to services in their local community; • Empower families to have effective relationships with service providers; • Train service providers on how to build effective relationships with families (including listening and responding to families' needs, showing respect, earning trust and avoiding judgement); • Provide cultural awareness training to service providers and teach them how give information sensitively and effectively; • Target hard to reach families; and • Recognise that families go beyond parents to include siblings, grandparents and extended relatives. Welcome friends to act as supports for parents/family members. Be flexible with meeting times to ensure both parents or a support person can attend with the primary carer. (Bartley 2006; Bellin and Kovacs 2006:213; Carpenter 2000; Gardner and Harmon 2002; Morison et al. 2003; Patterson 2002; United Kingdom Government Department for Education and Skills 2002).
Family time and routines	• Assist families to adapt routines and refocus goals when required and to deal with unexpected situations; and • Let families drive this support – practitioners should avoid defining family functioning patterns because these will vary by family and differences in race, culture and ethnicity (Patterson 2002:356).
Hope	• Focus on what families can be hopeful for; and • Assist families to develop or maintain hope for realistic outcomes and to change the nature of these hopes as situations emerge. (McCubbin et al. 1997; Morison et al. 2003:129; Patterson 2002).

Key protective factors for families	Examples of practice elements
Flexibility	• Assist families to adjust regarding changes to functioning – rules roles, meanings and/or lifestyles. (McCubbin et al. 1997; Parker 2001; Patterson 2002).
Financial management*	• Provision of adequate financial support to meet needs of the child with a disability, so families can meet these needs, are not in financial stress or sacrificing other family members' needs; • Provision of equitable access to child care and support for the child to access therapies and medical appointments, so parents can work desired hours; • Information and linking of free supports, such as toy libraries; and • Provision of financial management skills training (where required). (Bartley 2006:15; McCubbin et al. 1997)
Truthfulness	• Active information sharing between service providers and families; • Assist families to access and understand information and share it with other family members (including siblings); • Hold group meetings where both parents or more than one family member can attend (this may have to occur outside of business hours); and • Provide information/resources that are age appropriate for siblings.
Equality and empowerment	• Actively involve families in discussions and decision making. Talk 'with' families, not 'about' them or their child (Dobson et al. 2001:25); • Assist families to build capacity to advocate for their child (education about rights, knowledge of supports available, support regarding how to advocate, support from community, such as other parents in similar situations); • Perceive, acknowledge and treat parents as experts of their child and be sensitive to their emotional side as parents; and • Encourage and train parents and service providers to form partnerships that include negotiation and reciprocation. (Carpenter 2000:135; Dobson et al. 2001; Patterson 2002:357; Roberts and Lawton 2000:307; United Kingdom Government Department for Education and Skills 2002)
Spirituality/ meaning	• Referral, access to or provision of counselling by a professional who understands the situation families with a child with a disability may be experiencing.
Health	• Provide families with the opportunity to look after themselves physically and mentally by offering periods of respite care so parents can rest and participate in recreation.

The practice elements listed above are applicable to family centred, clinical (psychology and psychiatry) and medical (therapists, doctors and other health professionals) service models. However as many of the practice elements that address one protective factor cross models, without some co-ordination or integration, support may be less effective. Research shows that co-ordination between services is key for the disability sector, but currently poorly implemented (NSW Ombudsman 2006). Carpenter (2000:141) suggests disability services supporting families should move towards a 'transdisciplinary approach' where professionals focus on supporting families holistically, not just in their area of expertise. Scott similarly suggests that 'the separate silos of health, mental health, education and welfare … be bridged at the policy creation, program development and service delivery levels' (Scott 2001:77).

One example of co-ordination in Australia is the Early Childhood Intervention Coordination Program (NSW Ageing and Disability Department et al. 1999). Another example is within the United Kingdom where a 'key worker' model is used. The key worker connects families to a range of supports and helps to facilitate communication between support providers. The Sure Start (2002) program nominated the inclusion of a 'key worker … for each child to provide a co-ordinated service' as best-practice in supporting families where a child has a disability. European research has also found some family-centred models facilitate 'close collaboration between the range of professionals in the fields of pedagogy, psychology, social services and medicine' (Peterander in Carpenter 2000:138).

3.5   Examples of existing services that have been evaluated

It is difficult to identify good-practice services that support families where a child has a disability because so few services have been evaluated (Ferdanez 2004), especially where those services are early prevention based, rather than reacting to families in danger of placing a child (or having a child placed) in the care of the state. Nonetheless a review of some national and international evaluations is described below.

Australian

One Australian service that has been evaluated is the Paediatric and Adolescent Support Service (PASS) in Victoria. This is a therapeutic model of support for families of children with chronic illness or disability. The therapeutic model is a mix between a family-centred and medical/clinical approach, which can be best described as psychosocial. The service focuses on addressing the trauma families experience as a result of the illness or disability. Counselling, psychological first aid, peer groups, parent mentoring, social events and community education are provided to assist families to strengthen their resilience through coping strategies, such as hope, re-establishing control over their daily lives and connecting or re-engaging with social networks (Morison et al. 2003:125). PASS offers separate interventions for children and adolescents with a chronic illness or disability, their parents and siblings, as well as group activities. The model allows families to come into and out-of the service at their own discretion, recognising that families will progress through phases where they will and will not require support (Morison et al. 2003:129).

PASS provides interventions that address a number of the key protective factors for families: problem solving, family hardiness, social support, hope, empowerment and meaning. For example, families are offered counselling (which covers numerous areas including coping strategies); they are linked with other families in the community; are assisted to identify areas of hope; are empowered through sharing their experiences with other families, the provision of information and opportunity to make decisions regarding the support they receive; and families are helped to 'reframe' their situation and find some meaning (Morison et al. 2003:129)

Another example of an Australian program that has been evaluated is Signposts - an intervention program for parents who have children with disabilities and challenging behaviours. The evaluation found that parents who completed the training were 'less

stressed, felt more efficacious about managing their children's behaviour, were less hassled about meeting their own needs and that their children's behaviour had improved' (Hudson et al. 2003). This program also assists families to strengthen their protective factors, but unlike PASS, focuses only on one area. Similarly, the Stepping Stones Triple P, which 'aims to assist parents develop practical solutions for common and potentially stressful behavioural and developmental challenges', has been found to effectively support families (University of Queensland).

Many other services in Australia that focus on the family, rather than just the child with the disability, are for families deemed to be at risk of breaking down or relinquishing care for their child with a disability (National Disability Administrators 2006; Senate Community Affairs References Committee 2005:140-1,153). While these supports are essential, they are reactive programs. Further research is required to identify good-practice Australian services that meet the criteria listed above and serve to strengthen families at transition points to assist during the resilience process, not just intervene or react once the family has not recovered or adapted.

International

The 'key worker' model used in the United Kingdom has been found to be successful for some families. The model provides families with a 'key worker', or a case manager, who offers practical and emotional support. Families are assisted to attain information, meaningfully access services and co-ordinate supports. Key workers visit families once or twice a week and help them access, work with and link together a range of support services, such as physio, speech and occupational therapists, paediatricians, general practitioners and other health professionals, as well as social services, education and parenting programmes. This is a true family-centred model because instead of providing support services for the child with the disability and attempting to provide peripheral support for parents, it is based on the premise of supporting parents within the home (Carpenter 2000:138-9). In reviewing research that has evaluated this program, Liabo et al. (2001:5) found that families connected to a worker were less stressed, had better access to benefits and more positive relationships with service providers.

3.6   Conclusion

The interactions families have with service providers and the support they receive can assist to maintain, strengthen or negate family resilience. Therefore service providers have the capacity to work with families to assist them throughout the resilience process. Their role is especially important in regard to assisting families to establish, build and draw on protective factors, or resources and strengths, within the family and community. Service providers can implement elements of practice that assist families to solve family problems and balance relationships; strengthen family hardiness; build, maintain and use social supports; develop, maintain and adjust family routines; and identify and develop areas of hope. They can also facilitate or provide assistance in the areas of financial management; truthfulness and transparency of information; equality and empowerment; finding meaning; and health. These practice elements cross family centred, medical and clinical models of support. Therefore best practice is where services are co-ordinated and are preventive and interventionist; supporting families throughout the resilience process,

not just once they are in danger of dissolution or of forfeiting the care of their child with the disability to the state.

4 Measuring family resilience

This part of the report explores the practicalities of measuring family resilience where a family includes a child with a disability (0 - 8 years). Both clinical and social disciplines were canvassed to identify appropriate, good-practice assessment tools. While numerous tools exist for researchers and clinicians, there are limited options for practitioners working with families. While these practitioners may be committed to using an asset-based approach and strengthening families, there is 'a giant gap' in regard to 'adequate assessment tools to help recognize family strengths' and therefore limited knowledge about these strengths (Marsh 2003:147).

Therefore this part of the report deals with the challenges, problems and limitations for practitioners when attempting to measure family resilience and the reliability of these tools. It provides examples of researchers and service providers who have developed, used and evaluated family resilience measurement tools; and it offers ideas of how service provision can move forward in regard to working with families on resilience.

4.1 Problems and limitations of family resilience measurement tools

There are a number of challenges in developing a standard, useful tool to measure family resilience. In fact, Walsh discounts a 'blueprint for any singular model of "the resilient family"' (De Haan et al. 2002:277). If family resilience is measured, it needs to be done so over time. Conducting an assessment at a single point will only look at a family's risks and strengths at the time of the test. Multiple assessments are important because 'families may look like they are coping at one point in time, when in actuality their coping patterns are destructive in the long run' (De Haan et al. 2002:286).

Family resilience is based on the family as a group, along with how individual family members perceive situations and how they behave. Therefore family resilience needs to be measured across the family as a group, rather than assessing a single family member (De Haan et al. 2002). This is practically and statistically difficult because the primary carer will most likely be the family member available for assessment with a practitioner, and, even if other family members (such as a secondary carer and siblings) are available for an assessment, then weighting the family's responses to elicit a single measure of the family's resilience is complex.

Even if an appropriate tool can be developed that measures resilience over time and is based on all family members, the reliability of the measurement may be affected by the practitioner administering it and/or the perceptions of the family. The social context of where the assessment is completed could affect the results, along with how each family member understands the 'key concepts' within the questions researchers or practitioners are asking (Howard et al. 1999:307). Family responses may be tailored to achieve a certain outcome from the assessment. That is, if a family believes that the results of the assessment may affect their access, frequency, duration and intensity of support, they may amend their answers. Similarly, if families are concerned about a practitioner judging them or possible intervention from the state, responses may be positively skewed.

Finally, standard measurement tools also have the potential to 'overlook' the functioning, strengths and protective factors within families of different races, ethnicities and cultures and families living in differing geographic locations (De Haan et al. 2002:289; Patterson 2002:356; Silberberg 2001:55). Despite these limitations, some researchers and practitioners have developed, used and/or critiqued family resilience tools.

4.2   Examples of researchers and practitioners developing, using and evaluating measurement tools

De Haan et al. (2002:276-7) recommend a longitudinal tool that assesses families before, during and after a stressful event to look at the 'trajectory' of resilience. But they acknowledge that measuring the family as a whole is virtually impossible because even by applying weights and amalgamating individual scores, 'we are still obtaining the reports of individuals; we are still gathering data at the individual level and extrapolating it to the family level' (De Haan et al. 2002:279). They developed a quantitative tool, nonetheless, that relies on data collection prior to the stressful event, during the crisis and after the family has adjusted (2002:286). De Haan et al.'s tool does not 'label' families with a level of resilience, but looks at 'the multiple paths families may take'. Their method is comprehensive and validated, but it is a complicated tool for practitioners to use because it requires numerous family members to be available before, during and after a crisis for assessment and it relies on the practitioner having statistical skills to calculate resilience.

Orthner et al. (2004:162-3) also developed a tool – the Family Strength Index – to count a family's assets. Twenty-three assets were covered within five spheres of strength: economic, communication, problem-solving, social support and family cohesion. The scores (where an asset is deemed present) were aggregated to determine whether a family had strength in a certain area. While this tool covers many of the protective factors outlined in Table 1, it is not a tool to measure family resilience, because resilience is not only based on the protective factors a family has to draw on, but also the crisis, event or trauma and the how the family reorganises and recovers (as described in Section 2.4).

The Family Action Centre at the University of Newcastle similarly developed the Australian Inventory of Family Strengths (85 positive statements) and a Family Strengths Survey (14 open questions) (Silberberg 2001). From the results of the inventory and survey an Australian Family Strengths Template was devised, which includes eight qualities: 'communication, togetherness, sharing activities, affection, support, acceptance, commitment and resilience'. Despite this framework, Silberberg (2001:53) warns against practitioners using the template or inventory to measure family resilience. She argues that 'family resilience can not be found by simply ticking of a list of qualities' or by having a standard model.

Finally, Gardner and Harmon suggest that the ten themes identified in their mothers, who were experiencing resilience and had children with disabilities, could be used by practitioners to:

> help all families to identify their strengths; to assist them to identify and
> develop key skills or qualities; [and] to give them hope that they can

regain control of their lives in the fame of the extreme demands of having a child with a disability.

The ten themes include: 'developing a sense of self'; 'the emotional journey', 'being a team'; 'the power to act'; 'being organised'; 'using supports'; 'my cup's half full'; 'I also have needs'; 'no one misses out'; [and] 'making sense of life' (2002:63-8). A number of these themes are included in the list of protective factors and are important characteristics, but again this merely provides a tick box list of strengths (the limitations of which were discussed above). Also, since the women identified as experiencing resilience by Gardner and Harmon are strong in all of the ten areas, having such overwhelmingly positive family examples could reinforce helplessness in families where these themes are low or missing at the time of assessment.

4.3   Should family resilience be measured and what are the other options?

Identifying a standard tool, or a range of tools, for practitioners to measure family resilience is problematic. For validity, assessments need to be conducted over time, they have to be sensitive to different family situations and context and all family members require some involvement and results require weighting across the group. In addition, family members' perception of the purpose of the assessment and their understanding of individual questions, along with the social context of the assessment process, can affect the results. Even where psychometric tools have been validated, for family practitioners to use them requires expertise, training and ongoing expense.

There are also some risks involved with measuring a family's resilience. Measurement may individualise resilience (making it the family's responsibility), rather than an ecological or social situation. A lack of protective factors, for example, may reflect a family's opportunity or socioeconomic status, rather than their psychological state or coping skills (Bartley 2006:6). Yet the process of measuring a family's resilience and assigning an outcome from that measurement may connote individual, rather than broader social responsibilities.

There is also a risk that measurement tools will render scores or labels that highlight a family's dysfunction. For some families, being identified as having a 'low resilience' could be damaging for families who are already very vulnerable. Silberberg (2001:55) points out the dangers of measuring and labelling families. She also discourages practitioners from testing families and trying to teach them 'a set of strength practices'. Instead, she advises fellow practitioners, 'our task is to facilitate families in the process of identifying their own strengths' and using tools, like the Australian Family Strengths Template, to develop 'resources and programs' (Silberberg 2001:53,55).

Even where a label is not applied, the measurement process could reinforce the limited resources and strengths a family has to draw upon, the crisis they are experiencing and their feelings of helplessness. Walsh argues that strengths frameworks 'should identify key processes that can strengthen each family's ability to overcome the challenges they face', and not look for a model of family resilience or a check list of strengths (Silberberg 2001:55). The difficulty is that further research is required to understand these 'key

processes' in terms of how families recover, rather than just identifying the strengths that assist them (Patterson 2002:358).

If a practitioner's or service's objective is to work with families to assist them to maintain, build or strengthen their resilience, using a measurement tool may not be an appropriate strategy. Options that are of less risk to families and do not necessarily have the validity problems of a resilience measurement tool, include training for service providers on an asset-based or strengths approach; incorporating good practice elements (some examples are listed in Table 2); working with families to understand the level of disablement they are experiencing (in terms of social exclusion) and identifying practical strategies and providing resources to improve social inclusion; and providing access to a range of supports and services, such as parenting programs, relationship support and counselling (Stewart-Brown 2006). While a tool may assist to identify families most in need of support, public health research has found that universal (access to all families), rather than targeted approaches, are more useful. Universal prevention and intervention programs decrease stigma, provide help to all parents who want assistance, increase the capacity for parents to help other parents and assist greater numbers of people to improve their family functioning (Secombe 2002:384; Stewart-Brown 2006).

4.4   Conclusion

While tools that measure family resilience have been developed and used by researchers, they are problematic for practitioners working with families where a child has a disability. This is primarily because measurements need to be taken before, during and after a stressful event with all immediate family members (and, since these events are likely to occur on multiple occasions, this three stage assessment would need to be ongoing) and the results require complex analysis. Reliability of these tools can also be compromised by the social context of the test, how the practitioner administers it, and how family members interpret the questions and the purpose of the assessment. In addition, measuring a family's resilience may also place the family further at risk by reinforcing their vulnerability, limited resources and helplessness. Therefore measuring family resilience may not only be meaningless for service providers, but also damaging for families. Consequently, family resilience experts usually advise against using these measurement tools in a practical setting.

Service providers, however, can implement practical approaches to work with families on resilience. Some of these practice elements include staff training, building and/or strengthening protective factors (such as working with families on improving social inclusion), and providing parenting programs and counselling support. A universal approach, where all families have access to quality, needs based support, may assist families through the resilience process. The next phase of this research will include focusing on what services can do to support families in the resilience process.

5 Phase Two – primary data collection

This report is the first phase of the research. The second phase will involve interviews with families who have a child (0 - 8 years) with a disability and key stakeholders. These interviews will examine both the resources families have access to – support provided within and outside of the family – and their strengths, such as emotional well-being. This phase of the research will examine how families can best be supported at the first point of contact with service providers and at other key transition points to improve the child and families' outcomes. This part of the research will also identify and talk with key stakeholders in Australian states and territories, such as service providers, government officials and professionals working with families where a child has a disability. These interviews will inform the understanding of how families can be practically supported in the process of maintaining, building and strengthening their resilience.

6   Conclusion

Family resilience can be defined by three major criteria – the family experiences a traumatic event or stressful situation (sufficient to place that family at risk); the family has protective factors, or resources and strengths, that they can use to help them adjust to the event or situation (and there is an outcome that is achievable for that family); and the family recovers by adapting their functioning where required (even though there was a chance that the family might not adapt). Each of these criteria are required if a family is to experience resilience. Therefore a family can not go through the resilience process if any of these conditions are absent. And, as resilience involves a series of steps, it is a process that families go through, rather than a trait. Consequently, family resilience can change over time and is a path that families can experience on multiple occasions. This is especially likely for families where a child has a disability because each transition, life stage or assessment can be stressful.

Before service providers start to work with families on the resilience process, certain foundations need to exist. Families require resources and strengths to draw on as protective factors and therefore financial and social disadvantage necessitates redress and counselling support may be beneficial. Social policies and service provider practice can assist families to maintain, build and strengthen critical protective factors. Factors found to be most important for families with a child (0 - 8 years) with a disability are family problem solving and balanced relationships; family hardiness; social support; family time and routines; hope; and flexibility. Other areas of importance include financial management; truthfulness and transparency of information; equality and empowerment; finding meaning; and good health. Practical approaches to support families in each of these areas were provided in Section 3.4. These practice elements cross family centred, medical and clinical models of support.

Service provision can be most effective when the approach is co-ordinated, as evidenced in the United Kingdom by the 'key worker' model, and a prevention and intervention framework followed. These key workers assist to inform, link, co-ordinate, follow-up and refer families, which has been found to decrease stress and protect families. Support for families who have been through the resilience process and have not recovered, are in danger of dissolution or of forfeiting the care of their child with the disability to the state is critical. However services should also be prevention-based and direct support to assist families throughout the whole resilience process. Support could be most effective if service providers work with families prior to, during and after stressful events or transitions and if family resilience is recognised as potentially transient.

While tools to measure family resilience could be theoretically useful to service providers, from a practical perspective they are limited and problematic. Clinical tools have been used by researchers to measure family resilience, but these require training, measurements taken at multiple periods with all family members, complex analysis and, usually, ongoing expense. Reliability of these tools can also be compromised by how family members interpret the questions and/or purpose of the assessment, the context of the test and how the practitioner administers the tool. Measuring a family's resilience may also further place the family at risk by reinforcing their vulnerability, limited

resources and helplessness. Each of these challenges, limitations and problems has largely left experts advising against the use of tools to measure family resilience.

Other options that may assist service providers to implement practical approaches to work with families on their resilience include training for service providers, focusing on building and/or strengthening protective factors, and providing parenting programs and counselling support. A universal approach would assist greater numbers of families with a young child with a disability throughout the resilience process, ensuring a broader preventive and interventionist approach.

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