Chapter 13
Building Strengths and Resilience: Supporting Families and Disabled Children

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Introduction

The provision of effective support to families is a community concern and is closely connected with issues of rights and citizenship. Effective support enhances resilience and contributes to the full participation of disabled children in all aspects of community life. In the disability field policy makers and practitioners have, over many years, worked to define the philosophical thinking behind service provision and develop appropriate resources and programmes that meet the needs of families and of disabled children. Decisions about support and services are constrained by issues of resource allocation which means those charged with developing services need to have clarity over what works and what actually makes a difference in people's daily lives. Service engagement can be overwhelming for families; however, when practitioners are respectful and responsive they have an important role in supporting families to build agency and take control over their circumstances. Medical practitioners provide treatment and interventions that respond to a child's medical and health needs, but they also have a key role in assisting families to make sense of their adverse circumstances. They can support families to navigate to the right services at the right time. For example, medical practitioners facilitate pathways into other services, such as family support and education services.

In this chapter resilience and the provision of family support is considered from the perspective of social and community work practice. The ideas presented in this chapter draw on the author's practice and research with families over three decades. This chapter takes an ecological approach to resilience (Liebenberg & Ungar, 2009) and explores the experiences of families as they negotiate for medical services.

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Having resilience means that families can live meaningful lives, maintain a sense of control over their lives, and assert their rights as citizens to be included and to fully participate in their communities. The chapter begins with a discussion on the philosophical underpinnings of service provision for disabled people internationally. This is followed by a discussion on the challenges faced by families as they navigate to effective services. The next section takes an ecological approach and explores the approaches that can make a difference for families and children. Central to understanding the relationship between those requiring support and those providing this support, such as medical practitioners, is the recognition of the reciprocal nature of the support relationship. This relationship is perceived as a dynamic and complex relationship; successful partnerships between practitioners and families recognise the expertise of families and the skills they have developed in providing support to their children.

Disability, Support and Services

In the last three decades there have been major developments in the provision of support to disabled children and their families (Munford & Bennie, 2009, 2013). Several core ideas have influenced these developments; central to these are changes in the way disability is perceived including the rights of disabled people to experience ordinary lives (Ministry of Health, 2001). International conventions determine rights for disabled people and outline the resources they are entitled to, such as access to health services, being respected and having their dignity protected, and being supported to make informed choices about services.

Historically disabled people have been a disenfranchised group often excluded from defining their own needs and aspirations (Hallahan, 2010; Munford & Bennie, 2009, 2013). This experience for disabled people themselves has impacted on families who speak of the marginalisation they feel in their support roles as they struggle to locate adequate resources and cope with the negative responses of others who do not understand the needs and rights of disabled people (Munford, 1994a, 1994b). Over time the experiences of disabled people have been constructed by a range of perspectives that have functioned to define the nature of their impairments and their lived experiences including how services and support will be provided (Sullivan & Munford, 2005). The medical model has had a major impact on service provision and has its origins in the rise of medical science, economic rationalism and social Darwinism. The emphasis here is on disability as an individual problem; disabled people are viewed as the victims of personal circumstance and tragedy and the response to this focuses on diagnosis, prevention and personal adjustment (Munford & Bennie, 2009, 2013). Munford and Bennie (2009, p. 210) argue that "the medical model had a pervasive influence" and this has been "well illustrated by the large-scale institutionalisation of disabled people that occurred throughout the nineteenth and twentieth centuries". With institutional care being the dominant mode of service provision many families were encouraged to have little or no contact with their family member.

Criticisms of the medical model emerged in the 1960s and gave rise to new perspectives on disability including the social model of disability. This perspective had a profound influence on thinking about disability and has changed the approach to service provision (Sullivan & Munford, 2005). The social model regards social reality as a product of social interactions and disability is seen to be constructed through the interactions between disabled and non-disabled people. The construction of disability is one of deviance and deficit where disabled people have stigmatised identities (Munford, 1994b; Munford & Bennie, 2009). The social model provides an analysis of the situations of disabled people and challenges the way in which their lives have been constructed by others. Central to this is reframing the interpretation of impairment and supporting disabled people to create meaningful lives.

The social model of disability has been critiqued for not having a robust enough analysis of the impact of structural experiences such as poverty and inequality. Being excluded from participation, feeling honoured and having one's identity respected is often intricately linked to having access to what are deemed to be normative societal resources such as employment and education. Such a perspective reminds us that individuals are social and economic beings and that it is not only the ideas in a society that will determine how they are to be perceived but it is the access to valued goods and services that will also determine the quality of their life.

The emerging perspectives on the experiences of disabled people have challenged thinking on policy and practice. Rather than being viewed as the inevitable consequence of impairment itself, disability is regarded as the consequence of living with impairment in a disabling society. The problems faced by disabled people are located not within the individual but in a social milieu and disability is thus understood as a political problem. Here disabled people assert their right to define issues on their own terms and to determine a course of action that might lead to changes in the structures and policies that can then operate in their interests (Munford & Bennie, 2009, 2013). Disabled people have worked collectively to create a shift in power and resources and this has included families and others who support disabled people in their daily lives.

The challenges that families face in accessing quality services are complex and range from personal and familial issues to structural and service issues (Merriman & Canavan, 2007). These issues are connected with the aspiration of families to enhance their strengths and well-being and to build capacity and resilience that can be sustained over time. The next section addresses some of the challenges families and the person they support face in their daily lived experiences including being able to easily access services including medical services, without stigma. Central to this is being able to exercise choice over service engagement and to be treated with respect and dignity. Of utmost importance is the facilitative role services can have in opening up opportunities for families and children. Historically, as has been outlined in the previous discussion, services have acted as gatekeepers to community participation and have constructed the experience of disability in ways that have restricted opportunities. This experience remains a major challenge for families as they negotiate for support for themselves and for their child.

Family Life: The Challenges

This section identifies the challenges experienced by families and their children. The *strengths perspective encourages us to move from defining the issues families face as "deficits" to defining these as challenges that can be addressed with the right supports*, *networks and services including medical services* (Munford, Georgeson, & Gordon, 1994; Munford, Sanders, & Maden, 2012). This approach aligns strongly with the developments in the disability field which require us to "… reconceptualise the 'problems' facing people with disability as issues of citizenship, participation, opportunity and support" (Munford & Bennie, 2009, p. 210). The ideas presented in the following sections draw on the author's practice and research with families over several decades. A review of this work has identified a number of challenges for families and children as they work to find the right supports and opportunities so that they can fully participate as citizens.

Finding the Right Support

Families often struggle to find the right service for their child. Service provision is determined by a range of factors including policy alignment with organisational practices that may extend rather than restrict opportunities. A major challenge for families is being able to form relationships with medical practitioners that are based on respect and authenticity. Families have expertise and a deep understanding of the needs of their child. The challenge for practitioners is to recognise this and to harness this in interventions. Successful interventions recognise the expertise of the family with regard to their child's abilities, challenges and care needs. Such interventions maintain a family's sense of autonomy and agency and position them at the centre of decision-making about services and interventions.

For many families adequate medical support is simply not available. It can be difficult to access the right support at the right time and agencies may have limited funds to spend on developing services. The provision of support is likely to be variable and in rural and isolated areas the choices are restricted. Moreover families often need to do a lot of work themselves to locate appropriate support and often speak of their disquiet when they have to assert their rights for services. They can often feel humiliated as they outline their need for support and are required to constantly recount the challenges in their daily lives (Munford, 1994a, 1994b; Munford et al., 1994). For these families locating appropriate support is not a seamless process.

Achieving a Sense of Coherence

Given the daily challenges families face they often struggle to maintain a focus on the positive experiences in their daily lives. Practitioners can encourage families to find the strengths within their family and their wider network, but at times it is difficult for families to keep "body and soul together". Achieving a sense of coherence and meaning about their situation can be difficult for families as they work to achieve the daily practical tasks in the care of their child (for more on supporting patient's sense of personal intactness in a palliative care context see Goldstein, this volume). It can be immensely challenging to manage the needs of all family members and at times factors external to the family can put added pressure on family life. A significant pressure that can undermine their sense of well-being is being able to manage the way "difference" is defined. Discourses about family life that construct and define the experiences of disabled people in terms of deficits can place emotional pressure on the family. Despite the important achievements at the policy level the daily experiences of families are often imbued with added stress as they learn to cope with the negative responses to their family member's "different" identity. This "difference" can be negatively constructed and put pressure on families as they come to terms with others' interpretations of their family life.

Medical practitioners can intensify a family's feelings of being judged. The assessments required to ascertain service need and plan for interventions can mean that private experiences become open to a public gaze. At times these experiences are the focus of unwanted attention that is not only unhelpful but can be demeaning. Those outside the support relationship may perceive the support role as a burden and this in turn undermines the importance of this relationship and also devalues those within the relationship. What families tell us is that while the daily tasks can be challenging they are also rewarding and what is more likely to be a burden and create issues are the external factors in the support relationship, such as inadequate resources and the attitudes of others to their roles. For example, having practitioners recommend to parents that they should "take a break", but failing to support the family to seek out appropriate respite care for their child. A more helpful approach is to place value on the support relationship and to acknowledge its central role in enabling people to live in their local communities. Care relationships are part of the natural fabric of community life. Practitioners have a key role here by facilitating access to appropriate resources.

Also of significance for practitioners is developing an understanding of the nature of the care relationship. Care by family members extends beyond simple support. This kind of support can be understood as "extraordinary care" which is embedded in ordinary relationships as an everyday activity (Collings, 2009, p. 7). Family support has relational, affective and behavioural aspects and it is constituted of "labour and love" and of "activity and identity" (Collings, 2009, p. 7). Support in the family takes place in a relational context of commitment and attachment and a range of support is provided, including emotional, practical and financial (Collings, 2009, p. 7). Providing care is complex and multifaceted. Families will at times need to access the specialist skills and knowledge of medical practitioners and the nature of this will change as new needs emerge. Regardless of what needs emerge the family relationship will remain as a central relationship in a disabled person's life journey. Effective practitioners respect this and value the support families provide and acknowledge that it will be families who enable disabled children to have full and meaningful everyday experiences.

Despite medical practitioners' good intentions, families remind us that at times they fail to understand the significance of the caring role and the strengths and capacities families have developed in order to provide meaningful support to their child. In such situations practitioners need to be encouraged to think differently about family life and to understand that a focus on deficits and problems can mask the "multiple positions" families may occupy (Munford & Sanders, 2005; Sanders & Munford, 2010). While not denying the challenges and the daily struggles that families may face, families also want recognition of the diversity of family life; their experiences of disability is one aspect of family life and a focus on the other aspects can assist them to achieve a sense of coherence and meaning that helps them make sense of the daily tasks they need to achieve and the issues they need to confront.

Consistency of Support: Working with Practitioners

Families report that inconsistent and disrupted access to services can be a major challenge. Consistency of support takes many forms; a primary concern is having a consistent approach to service engagement so that there is no disruption to the quality of support provided. When there are changes in service delivery, including turnover of medical practitioners, families may face additional challenges; for example, being asked to brief new practitioners and explain their circumstances. Many families talk of having to cope with the added pressures of changes to service delivery; they recount stories about having to be flexible and prepared to learn about the latest ideas in service delivery. Some of these are very helpful and do have the potential to enhance support networks, while others require families to continually justify their entitlement to services as service specifications and thresholds change.

Families are required to understand and respond appropriately to the developmental changes in a child's life and need to negotiate services in a range of domains such as medical services, education services and specialist services (for more on providing developmentally appropriate care during the transition to adolescence see Lennon et al., this volume). Families take on multiple roles ranging from emotional to practical support. Practitioners may fail to recognise the complexity of the care role and may not acknowledge the knowledge, skills and expertise the family develops over time. While some families feel supported in their role and are acknowledged for what they have contributed, others feel that practitioners do not always recognise their skills, such as managing medication and clinical routines, developing communication skills, working on enhancing mobility, and helping the child work through identity issues. While many families would willingly have others complete these tasks, this kind of support is often unavailable so it rests on families to equip themselves with the knowledge and skills to effectively support their child. Given this experience, family caregivers should be seen as key members of the support team and not excluded from key decisions (Collings, 2009).

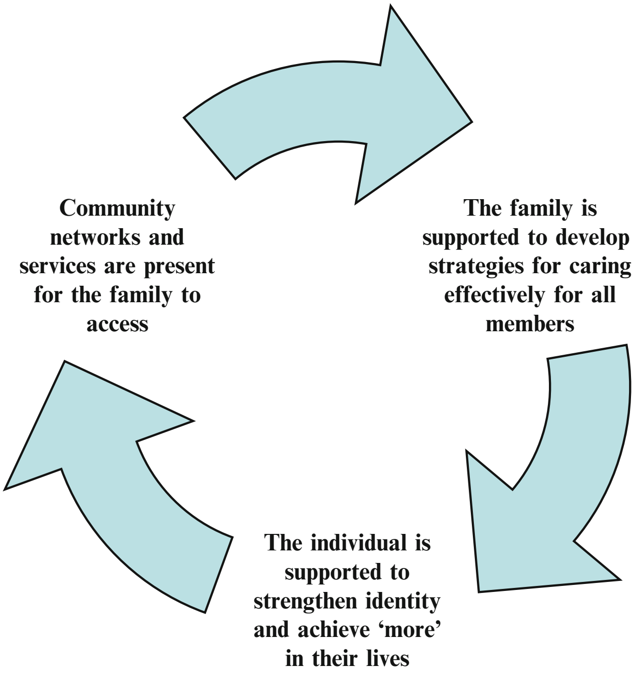
Some service systems still function to exclude disabled people and their families from decision-making processes. While it can be difficult to organise effective teams so that everyone can fully participate this needs to remain an important goal. Medical practitioners can facilitate the participation of families in key decision-making processes about service provision. This requires having skills in team work and facilitating teams in ways that enable equal participation of families and practitioners. Ideally all of those involved in providing support are viewed as an interdependent team. Here the disabled person is at the centre of an interdependent network whose members' knowledge and skills are equally valued and where all are recognised as having something positive to contribute. Families report that while medical practitioners may have discipline knowledge they are often lacking in other core skills such as facilitating teams and communication skills that enable them to effectively communicate with a diverse client population (Munford & Sanders, 2005).

This discussion has outlined a number of key themes that are present in the lives of families; these may create challenges for them as they mediate their caregiving role with other factors in their family life. The next section explores a range of strategies that contribute to building strengths and resilience in family life. These strategies are a foundation for building positive and productive relationships between medical practitioners and families and their children.

Making a Difference: What Works for Families and Children

This discussion focuses on three areas. Based on an ecological–transactional approach effective support for families and their children is perceived as an integrated system that focuses on the interaction between the family, the individual and the community, which includes both formal services, such as medical services, and informal networks, such as extended family support, and is informed by policy and societal systems and structures including the economy, political and social systems, and culture. The following diagram summarises this approach.

Building Family, Individual and Community Strengths and Resilience



The Family

Understanding Strengths and Capacities: Changing Our Perspectives

A strengths approach assists us to think differently about family life; to move from a focus on “problems” and “deficits” to thinking about what positively influences family life. A focus on strengths does not ignore risks or issues but encourages us to find solutions by seeing and thinking differently about family life (Munford et al., 2012; Munford & Sanders, 2008; Sanders & Munford, 2010). A key focus is to determine how families can be supported to develop strategies for caring effectively for all family members. Strengths approaches include the following:

- A commitment to the belief that families possess strengths and resources that can be harnessed in support processes.
- An understanding that practitioners need to invest in building effective relationships with families so that they can assist in harnessing strengths and resources.

- That labelling families as dysfunctional when they are not coping can mean that we do not learn and understand how families have survived and achieved success despite the challenges. This includes understanding the everyday lived experiences of families and the way they have mediated challenges including how they have resisted policies that have excluded them from participation in community life.
- That practitioners need to think about what it is that enables families to survive and grow and to understand that service systems can actually alienate families and make it more difficult for them to engage with services and locate support.
- That requiring formal support and access to services reinforces our interdependence as community members and should be perceived as a natural component of the fabric of community life.
- That practitioners need to be creative in assisting families to find solutions and obtain support, know how to work on multiple levels, and work collaboratively with other practitioners and service systems to ensure that both practical and emotional needs can be met.

Underpinning strengths approaches is the belief that all families have a right to an ordinary life and that it is unhelpful to perceive those who face enduring challenges as suffering human beings living tragic and sad lives that need to be “fixed” before they can participate fully in their communities. Families and their children do not want to be defined by their medical and support needs but want to be perceived as citizens who are included in the daily life of their community. Practitioners can be of significant help if they develop an understanding of the strategies that will make a real difference in the lived experience of families and their children.

Understanding Context

Understanding context includes learning how political, social, economic, religious and cultural factors influence family life and shape what it is possible for them to achieve. Taking a critical realist position it is acknowledged that there will be constraining factors in people’s environments but that there will also be opportunities for people to construct and define their situation and to create change for themselves (Guo & Tsui, 2010; Houston, 2010). Medical practitioners who fully understand the contexts of family life can assist them to find opportunities; central to this is developing an understanding of the frameworks families use to make sense of their worlds including cultural, religious and spiritual beliefs (for more on the importance of cross-cultural “resilience work” see Yi, this volume). Families can hook into these frameworks in order to learn how to gain a sense of control over their experiences and life circumstances.

Understanding context also means that practitioners challenge themselves to reflect on their own experiences and orientation to service provision and prepare themselves for working with families. This includes engaging in honest reflection on how much they know about the family's context and the communities in which they live. For example, do they understand the nature of community life and whether these communities are part of the network of support for the family or function to further marginalise and isolate families (Munford & Sanders, 2008)? Of importance is the service context and thinking about how this impacts on families. For example, do medical settings enhance or hinder interactions with families. Do service protocols support practitioners to form partnerships with families? Are the rights of families upheld by all practitioners across all services, such as the right to be treated with respect and dignity, the right to be informed about all aspects of service provision, and the right to be included in all decisions?

Harnessing Natural Supports

Families and their children are at the centre of their own lives and before they have entered into a relationship with a formal service agency they would have harnessed their own supports and developed knowledge and expertise on how to manage their situation. Families are not "blank slates" or the passive recipients of wisdom bestowed upon them by experts (Sanders & Munford, 2010, p. 38). Families know what has not worked for them in the past and they are the bearers of their own unique histories. When medical practitioners enter a family's world they must remember that they are entering a process that has already begun and they need to hook into this process, not undermine it. Their role is to assist the family to identify what it is they need and to follow through on any tasks and processes they have agreed to facilitate. At all times they must remember that they are a "visitor" in a family's life and no matter how complex issues are, it is the family who will be in charge of decision-making and the implementation of these decisions. As Gilligan (2004) asserts, practitioners need to understand that they are not the exclusive source of help. Successful work will occur when practitioners support families to harness the strengths within these contexts (Gilligan 2004, pp. 101–102). For example, medical practitioners have a key role in supporting families to identify how they can access supports in their local communities in ways that cause the least disruption to family life.

Understanding the Factors That Enhance Resilience

Building resilience and capacity will enable families to sustain support over the long term and achieve well-being for all family members. An *ecological perspective* on resilience foregrounds the interaction of key systems and their role in contributing to a family's resilience (Liebenberg & Ungar, 2009). Resilience is a function of the social ecology of an individual or family wherein environmental, cultural and social resources can create pathways for positive growth. Viewed in this way resilience is not only associated with individual attributes, but arises out of the interaction between individual factors and the social environment (Liebenberg & Ungar, 2009). Families will build resilience by being able to successfully seek out resources in their environments; to navigate to these resources and to negotiate for them in culturally meaningful ways (Liebenberg & Ungar, 2009). For example, a family who is experiencing stress can build resilience and the capacity to cope in the future by being supported to successfully find resources to help them in their support role and to negotiate for resources that match the specific needs of the family. If the family is able to successfully seek out support they will be able to build on this to address issues in the future. They cannot do this alone however as their environments have a key role in making available the resources they need to build resilience. To be effective these resources need to be available and families may need to be supported to use them effectively.

Medical practitioners have a key role in supporting families to develop resilience and enhance their capacity to cope with their care roles. Central to this is helping families work with support systems to determine their support needs and how they want services to work with them. Effective practitioners are able to support families to identify the skills they have and strengthen these. For example, families may successfully cope with the daily routines but their coping capacities can be enhanced if they are able to access respite care at certain times so that the needs of all family members can be met. Medical practitioners can also help families identify the interventions that have worked well in supporting their child and support them to ensure that these continue. This may require drawing other people into the family's network of support. Being able to clearly identify needs and have these met enables families to develop a sense of agency and control over their circumstances.

The Individual

Constructing Positive Identities

The disabled child is at the centre of service provision. Practitioners need to work to give the child opportunities to express their views about interventions and to be fully involved in decision-making. A key focus is enabling the child to construct a positive identity, to achieve a sense of coherence and be supported to achieve their goals and aspirations. The support relationship is critical in assisting the child to develop a positive and meaningful sense of self. The support provided needs to be respectful and practitioners need to understand the impact involvement in services can have on a child. For example, relying on others to assist you in daily living routines, needing to attend medical appointments, and being involved with many practitioners, can undermine self-efficacy and control over one's circumstances.

Practitioners have a key role in helping the disabled child and their family positively manage their daily tasks and interactions. They can also ensure that engagement with services is a positive experience.

Reciprocity

Positive engagement with services is achieved when relationships between practitioners and clients are based on reciprocity. Traditional conceptions of the provision of care viewed disabled people as needing protection; such a view positioned them as being passive in the support relationship, having things done to them not with them. Current thinking challenges this view and argues that practitioners need to work to make support acceptable and meaningful (O'Brien & Sullivan, 2005). Being able to build reciprocal relationships that are genuine and authentic provides a strong foundation for interventions. Reciprocity is enacted when medical practitioners work to establish rapport with the family and child and take the time to understand family life. Feeling valued by practitioners enables families and their child to fully engage with services and interventions.

Finding Possibilities: Creating "More"

Services are a valuable resource that enables families and their children to enhance their strengths and resilience. This in turn enables disabled children to achieve "more" and to realise their dreams (for more on understanding the role of hope and dreams in the lives of families who raise medically vulnerable children see Mattingly, this volume). As the preceding discussion illustrated disabled people have often been restricted in the choices they make and their aspirations have been focused on a narrow range of options. Current thinking focuses on enabling disabled people to participate in a range of experiences and for others to understand the multiple positions they may occupy. This kind of support from practitioners and other support networks is informed by "possibility thinking" or finding "more" for the person to experience (Handley et al., 2009). "Possibility thinking" provides new perspectives for understanding the complexity of social situations and it hooks into the strengths orientation of finding out what has worked for families and individuals in the past and using these to open up new possibilities for the future (Handley et al., 2009). It moves from a focus on coping with a situation to taking control of a situation; families and children build on success in addressing current issues to build strategies for dealing with issues in the future.

Medical practitioners are part of a team of people that can support "possibility thinking". Such an orientation requires them to listen for opportunities in an individual's story; attention to the small details may contain the potential to find solutions. Connected to this is the commitment to assist the family and their child to seek "more", to have big dreams and to envision different futures.

While providing appropriate support for a family and their child may be concerned with dealing with the immediate issues one must ask whether this support extends the capacity and resilience of both the disabled person and their family. Effective support can have a key role in advancing community participation and inclusion and it can extend opportunities and possibilities for growth. Medical practitioners have a key role in advocating for the removal of barriers that prevent full participation in community life. For example, facilitating access to physical resources such as equipment that extends mobility and seeking out funding that will enable a child to participate in a diverse range of community activities.

The Community: Services and Support Networks

Responsive, Flexible, Interdependent Networks of Support

The research on the provision of effective support tells us that to be successful support needs to be responsive and flexible. An important long-term goal is to develop an interdependent network of support that will enable families to seek out a range of options for support in the community via informal support networks and from formal services (Carers New Zealand & The New Zealand Carers Alliance, 2007; Merriman & Canavan, 2007). Successful service options acknowledge the diversity of family life and experiences and incorporate these into decision-making and short- and long-term planning. Families will experience conflicted feelings when seeking out services and these feelings must be recognised and acknowledged. They report that effective practitioners take the time to understand their needs and rights and that these practitioners are sensitive and respectful. Services need to be both person-centred and family-centred so that the needs of both the child and the family inform decisions about the way support will be provided (Merriman & Canavan, 2007). Those planning services need to find ways to develop collaborative partnerships with families so that their knowledge and ideas inform planning processes both in terms of what they specifically require for their family and in the design of services in general.

Relationships

Building strong relationships with practitioners are at the core of successful partnerships between families and practitioners. Relationships with services should not undermine a family’s efficacy and become yet another challenge that the family are required to mediate. Practitioners can add resources and value to family life. Respecting families’ expertise and competence provides a strong base upon which partnerships with medical and other practitioners can be built. Central to this is respecting the expertise that each partner brings to the relationship; for families it is knowledge of their child and for practitioners it is knowledge about impairments, effective interventions, programmes and resources. Building strong partnerships and working collaboratively aligns with approaches that are concerned with enhancing participation and citizen engagement in decision-making. Active participation of the family in decision-making about interventions is critical to their success.

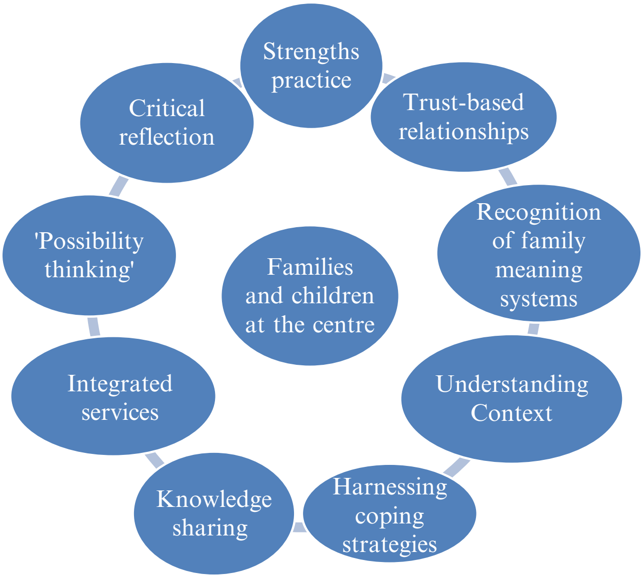
Effective practice grows from the recognition that when people have power and control over their circumstances they are more likely to be able to find positive solutions to their issues and challenges (Sanders & Munford, 2010). The next section presents a model of practice for medical practitioners who seek to build the strengths and resilience of families and their children. This approach embraces a collaborative approach to practice and places the family and disabled child at the centre of service delivery and networks of support.

Building Collaborative Partnerships Between Families and Practitioners

This final section brings together the ideas presented in the previous discussion and outlines a model for facilitating collaborative partnerships in medical services. Effective services are built around the regular and normal routines of family life. These services do not interrupt family life but respond in timely and appropriate ways and provide resources that enhance family life and well-being. Practitioners do not take over decisions for families but respect their autonomy. They work with families as equal team members and recognise that effective support is based on integrated and interdependent networks of support. By placing the person at the centre of the support system and acknowledging the diversity of family life it focuses on how support services need to be tailored to respond to the meaning systems of families so that all family members can experience well-being.

A collaborative orientation to planning for services emphasises joint agenda setting and identification of shared goals that take account of the needs and rights of all those involved. Key to this approach is recognising what families and disabled people bring to the planning table; alliances with families should be culturally responsive and respectful of differing meaning systems. Where cultural beliefs are a barrier to effective service engagement practitioners need to work sensitively and respectfully with families to support them to understand how interventions will contribute to positive outcomes for their child. Working in partnership with families enables practitioners to support families to identify what has worked for them in the past and use this knowledge to find solutions to current issues. Taking a collaborative approach means there is more considered thinking on an issue and when this is combined with attentiveness to opportunity and possibility, new and alternative strategies can be generated. This includes thinking differently about service provision and learning how to make the most of the available resources. The following diagram outlines the key elements of this approach.

Collaborative Partnerships



The following discussion summarises the key elements of collaborative partnerships between families and medical practitioners.

- The family and their child are at the centre of decision-making processes. This means they have a voice, they feel they are being heard and they are able to form positive partnerships with medical practitioners. Families have a key role in directing service provision and determining the nature of their relationship with practitioners and service systems. Their autonomy is maintained and strengths rather than “deficits” are focused on. Immediate issues are addressed but the orientation of service provision is to build the resilience of families and children in the long term.
- A family’s cultural frameworks and meaning systems are respected by medical practitioners. Generating connections with cultural and belief systems assists the family to gain a sense of control over their experiences and circumstances and enable them to seek support from those who know and understand their history and contexts. Central here is enabling families to seek out services that embrace their identities and meaning systems so that families can fully engage with services and interventions. For example, this may mean encouraging extended family members such as grandparents to be involved in interventions.
- Practitioners understand the way in which context influences family and community life. This involves understanding how political, social, economic, religious and cultural factors influence and shape what it is possible for families to achieve. Practitioners can support families to seek out resources and to engage

with positive change processes that will assist them to mediate the structural factors that function to restrict opportunities and exclude them from full participation in community life. For example, gaining access to financial support and resources that support interventions with their children.

- Medical practitioners take care not to disrupt the natural coping mechanisms that have been developed by the family and should build upon what has already been established within the family. These natural coping mechanisms promote autonomy, self-determination and enhance resilience. For example, families may have developed a strong network of support and these individuals can be encouraged to become part of the intervention and enhance their skills so they are equipped to be of the most help for the family and child.
- A key element of collaborative partnerships is the sharing of diverse knowledge. This orientation to service provision gives prominence to the idea that learning, growth and change are inherent human capacities and that all people are simultaneously learners and teachers. At the heart of practitioner and family partnerships are respectful learning relationships. This idea is closely related to the notion of reciprocity which recognises the knowledge and skills families have developed over time. Families, given their experience, can assist practitioners to learn about what constitutes effective support and practitioners are able to impart knowledge about impairments and interventions to families that is delivered respectfully and sensitively.
- Central to collaborative partnerships between practitioners and families is the provision of integrated services that enable the child and their family to enter into relationships with service systems that are themselves integrated and collaborative (for more on how the structure of medical services influence children's well-being, see Ungar, this volume). Here service systems are prepared to engage with their communities and to work in partnership to ensure that service provision is responsive and does not create barriers that disrupt the achievement of successful support relationships. This may require that medical practitioners hold their "professionalism lightly" (Munford et al., 2012, p. 71) and are prepared to be flexible and open to innovative and creative solution-finding processes that seek to enhance their relationships with families. For example, this involves welcoming families and practitioners in other services (for example, teachers) as equal team members who bring knowledge and skills to services which can be harnessed to provide more effective and responsive interventions.
- Collaborative partnerships respond to the immediate and practical needs of a child and their family and have the potential to contribute to strengthening a family's support network in the long term. These partnerships are a mechanism for opening up opportunities for inclusion and participation. The principle of "more" and "possibility thinking" constructs the support relationship as an opportunity for the disabled person and their family to engage in transformational change where visions and aspirations can be achieved. A collaborative partnership while focusing on the immediate and short term will also be future-focused as it is this thinking about what is possible that will realise the goals for citizenship, inclusion and full participation in community life. For example, providing learning

resources and managing medical routines so that a child can attend school in their local community which then enables them to create a learning pathway for realising their long-term goals.

- The realisation of collaborative partnerships requires ongoing critical reflection (Munford et al., 2012). Here the family and practitioners create mutually agreed processes that enable all partners in the relationship to reflect on the partnership. Such processes are an integral component of service relationships; it requires open-mindedness and a commitment to thinking deeply about what is working well and how practices can be improved. It is often in this space of critical reflection where thinking of "more" and "possibility thinking" is enacted.

In Conclusion

This chapter has focused on the relationships between medical practitioners and families and their disabled child. It identified the factors that build strengths and resilience and enhance well-being. It began with a discussion of the historical influences on the construction of disability and the provision of services. The discussion on philosophy highlighted how impairment has been defined and interpreted and how disability has been constructed throughout history. Dominant thinking about impairment and disability has changed over time and this thinking has determined the position of disabled people in our communities and influenced service provision. Changes to service provision have impacted on family life and the move to community-based services resulted in a change in role for families as they took on the major caregiving role and the support of their family member. To do this successfully they became experts in a range of areas and learned how to be strong advocates for their family member so they could gain access to appropriate support and services.

The second section discussed the issues for families as they worked to find effective support for their child and as they engaged with medical services. Families have become experts in "caring for" their child while maintaining other family relationships and routines. Of significance is finding appropriate resources that will enable families to sustain care over a long period while maintaining their own health and well-being.

The third section outlined a number of key factors that contribute to effective service provision and the key role for medical practitioners in supporting families. This requires a "different" way of thinking about service provision and a "different" orientation to practice with families and children. The idea of collaborative partnerships between medical practitioners and families was proposed as one approach to providing effective support as it keeps the family and the disabled person at the centre of decision-making and takes a collaborative approach to service planning and provision. Such an approach has the potential to advance the interests of the disabled child and their family by encouraging interdependence and contributing to the inclusion and participation of children in their communities. Here medical services have a key role by developing positive and nurturing relationships with families and children. These relationships are a key resource in supporting families to build strengths and resilience that enhances their health and well-being and enables their children to realise their dreams and aspirations.

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