Supporting families:

Building strengths and resilience

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Abstract

This paper will explore how we can effectively support families/whanau and build nurturing and inclusive communities. It presents an approach that builds upon the strengths and competencies of families/whanau and begins with learning about what effective support means for them and for the person they are supporting. It adopts a citizenship approach that is based on understanding the diversity of family/whanau life and focuses on how support services and systems can strive to uphold the rights of all family/whanau members to experience wellbeing. The main learning points for this presentation include understanding how strengths approaches encourage practitioners to support families/whanau to develop resilience. Central to this is learning how services can directly respond to the requirements of families/whanau and do not, albeit often unintentionally, act as barriers to inclusion. The paper explores how strengths perspectives contribute to collaborative practice including how practitioners can form authentic and respectful relationships with families/whanau that enhance their coping skills and build long term strategies for enhancing family/whanau life. The provision of effective support to families/whanau is a community concern and learning to do this well is part of learning how to promote diversity and full participation of disabled people in all aspects of community life.

Introduction

The provision of support to /whanau is closely connected with issues of rights and responsibilities and of citizenship and what the right to participate actually means in the daily life of disabled people and their families/whanau. It has been of concern to policy makers and practitioners over many years as they work to define the philosophical thinking behind service provision and then translate this into practice by providing the appropriate resources and programmes that meet both the needs of families/whanau and of disabled people themselves. Often decisions about support are about issues over resource allocation which means those charged with developing services need to have clarity over the philosophy of support and on what works and actually makes a difference in people's daily lives. This paper will explore some of these issues and outline some of the approaches that can make a difference for families/whanau and those they support. It is based on direct experience of providing support and also on research on support systems for families/whanau.

While the focus of this paper is on support systems for disabled people and their families/whanau the ideas discussed here have much relevance for other support experiences, such as people living with mental illness and their support networks. In exploring the factors that contribute to building strengths and resilience the needs of those seeking support and those who provide support are considered. Central to understanding the relationship between those requiring support and those providing this support is the recognition of the reciprocal nature of the support relationship and what it means for both partners. This relationship is perceived as a dynamic and complex relationship where all participants contribute to the relationship.

Historical influences on disability, support and services

Internationally there have been major developments in the provision of support to disabled people and their families (Munford and Bennie, 2009). These developments are closely connected to changes in the way disability is perceived and to understanding about what constitutes citizenship and the rights of disabled people to experience ordinary lives (Ministry of Health, 2001). In Aotearoa New Zealand these challenges from disabled people and their support networks have led to the creation of strategy documents such as the New Zealand Disability Strategy that are connected to international conventions on the rights of disabled people (Ministry of Health, 2001). The challenges have centred on the construction and meaning of disability and have called for disability to be viewed as a set of experiences rather than as a pathological condition; such a perspective views impairment as a natural part of the diversity that constitutes the human condition. Consequently the term 'disability' describes a wide range of experiences that people with impairments encounter in a 'disabling society'; such as poverty, marginalisation, lack of opportunity and choices and overt discrimination.

Philosophical perspectives

Historically disabled people have been a disenfranchised group often excluded from defining their own needs and aspirations (Munford and Bennie, 2009). This experience for disabled people themselves has impacted on those who support them in their daily lives. Many families/whanau and other support people will 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; Munford, 1994b; Munford et al., 1994). 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 and 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 and Bennie, 2009). 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 families many families/whanau were encouraged to have little or no contact with their family/whanau member.

Criticisms of the medical model emerged in the 1960s and gave rise to new perspectives on disability including the social model of disability and normalisation. Both perspectives had a profound affect on the thinking about disability and changed the approach to service provision (Sullivan and 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 and Bennie, 2009; Munford 1994b). 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.

Alongside of the development of a social model of disability, the experiences of people with an intellectual disability have been influenced by the adoption of normalisation principles which have informed service provision since the 1970s. Key proponents of this perspective, Nirje and Wolfensberger, argued for an approach that

challenged the practices of institutionalisation and supported people to lead culturally valued lives within the community. By living in the community and engaging in culturally normative experiences the lives of people with an intellectual disability would be enhanced (Sullivan and Munford, 2005). Both the social model of disability and normalisation principles have been critiqued as being contradictory, in that while there is acknowledgement of people's differences, interventions are likely to seek to minimise diversity and assimilate disabled people into the dominant culture without recognising what it is they bring to this culture. These actions may unintentionally devalue disabled identities (Munford and Bennie, 2009).

Moreover the social model of disability and normalisation principles have been critiqued for not having a robust enough analysis of the impact of structural experiences such as poverty and inequality. Being excluded from participation and 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. A political model of disability as with the social model of disability focuses on how impairment is interpreted and defines disability as something people 'experience' not 'have'. This model reminds us that individuals are social 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. This model traces its origins to critical theoretical traditions such as critical realism (Jones-Devitt and Smith, 2007) and postmodernist thinking (Munford and Bennie, 2009). It incorporates a view of the social world as one of irreconcilable differences and these differences arise out of conflicts between those who have power and resources and those who do not. Power relations operate at a number of levels including at the level of government, within services and within relationships (Munford and Walsh-Tapiata, 2006). 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 problem is located not within the individual but in a social mileu and disability is thus understood as a political problem. An analysis of the political positioning of disability generates a framework for resistance and challenge (Sullivan and Munford, 1998). 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 and Bennie, 2009). Disabled people have worked collectively to create a shift in power and resources and this has included families/whanau and others who support disabled people in their daily lives.

This discussion has presented some of the multiple perspectives used to define impairment and construct disability across time and context. The experience of living with impairment is complex and is connected with how societies organise themselves and determine how individuals are perceived, how they will be supported and the roles they will play in their communities. To fully understand how disabled people live their lives one must take account of all of the factors that contribute to all of their experiences in different contexts and over time. Hallahan (2010, p. 127) captures this point well when she argues for "an intersubjective interpretative framework" that sees "disability as a complex, evolving situation". This approach calls for a nuanced approach that works with multiple meanings and experience of disability including *inter alia*: embodiment and what impairment means in the daily lives of disabled people; the oppression experienced within service systems that have functioned to exclude people from participation; issues that arise from the response of others to the impairment; and underlying all of these experiences "the desire to be honoured, respected, and supported alongside [other]…citizens" (Hallahan, 2010, p. 127). The interpretations used to understand the position of disabled people and the construction of disability determine the nature of policy development and service provision. The evolving political analyses of disability and the critique of how power operates and resources are distributed have functioned to challenge policies and service systems that do not support disabled people to fully participate in their communities. Alternative policies and practice are continually being developed and in Aotearoa New Zealand this has included the creation of a national strategy on disability. The challenge is in the translation of broad vision statements into effective policy and practice that does make a positive difference for disabled people and their families/whanau.

Policy development and service provision

In the last three decades in Aotearoa New Zealand the policies guiding the provision of disability services have undergone significant change. While there have been many debates about disability issues, disabled people and their families/whanau agree that

disability issues are now placed firmly on the policy and legislative agenda. For many the changes represent a commitment to some kind of positive change and that their lives are worthy of policy and practice attention. For generations many disabled people had been silenced, often living in segregated communities including large institutions and hidden from society. Disabled people are now visible and the "processes of legislative change and policy reform have crystallised the issues and allowed disabled people to challenge policies and services that function to exclude rather than involve them in the daily lived experiences of their communities in spheres such as work, education and recreation" (Munford and Bennie, 2009, p. 213).

In Aotearoa New Zealand the Disability Strategy, released in 2001, is one positive outcome that has emerged from sustained lobbying and represents a commitment from government to achieve a more inclusive society and eliminate the barriers to disabled people's participation at all levels of society. The strategy presents a vision of a society that highly values the lives of disabled people to fully participate and it provides an enduring framework to ensure that government departments and agencies consider disabled people before making decisions (Munford and Bennie, 2009). It covers key areas such as:

- Relationships with government and communities are based on respect and equality.
- There is a movement from exclusion to inclusion and full participation.
- Interdependence is valued especially the important relationships between disabled people and their families and friends.
- Human rights are a fundamental cornerstone of policy and practice.
- Diversity and culture are recognised and there is an aspiration to support differing goals and aspirations.
- Institutional services are eliminated and community-based services promoted so that disabled people can live in their own communities close to family and friends.
- The Strategy is based on an understanding that legislation and policy must result in actions that enhance rather than disable the lives of people with impairments.

Despite the many collaborative processes used to develop the Strategy and the positive developments that have arisen as a result of the Strategy, disabled people remain vigilant about measuring the impact of legislative and policy change. The Strategy also has much relevance for families/whanau and has opened up many new possibilities. The protection of human rights and the commitment to ensuring full participation in community life has provided a benchmark for families/whanau as they seek to find the best possible support system for their family/whanau member in community settings. However, access to support systems has not always been consistent across jurisdictions and for many families/whanau access to appropriate support services continues to be a challenge. While the move away from large scale institutions to community settings has enabled /whanau to be more fully involved with their family/whanau members many families/whanau still struggle to access resources. What the Strategy does do however, is provide a platform for putting these issues on the policy and practice agenda; the focus on human rights and on interdependence has been a key platform for families/whanau to assert their rights to access quality care for their family/whanau member. The challenges that families/whanau face in accessing quality services are complex and cover a broad range from personal and familial/whanau issues to structural and service issues. These issues are connected with the aspiration of families/whanau to enhance their strengths and wellbeing and to build long term capacity and resilience that can be sustained over time. The next section addresses some of the challenges families/whanau and the person they support face in their daily lived experiences.

Family/Whanau life – the challenges

The strengths perspective encourages us to move from defining the issues families/whanau face as 'deficits' to defining these as challenges that can be addressed with the right supports, networks and services (Munford et al., 1994; Munford and Sanders, 1995; Munford et al., 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 and Bennie, 2009, p. 210). The research on the experiences of family/whanau life reveals a number of challenges for families/whanau

and the people they support as they work to find the right supports and opportunities so that they can fully participate as citizens.

Putting policy into practice and finding the right support

For families/whanau the struggle is often centred on being able to find the right service for their family/whanau member. Service provision is determined by a range of factors including policy alignment with organisational practices that extend rather than restrict opportunities. In Aotearoa New Zealand where there is a commitment to disabled people and their families/whanau having appropriate access to services, assessment procedures and issues over entitlement can limit access and exclude some individuals (Sullivan and Munford, 2005). While policy guidelines may be appropriate assessment procedures may be focused on tightly circumscribed needs rather than on individual rights given that the service system must deliver what is economically feasible. In such conditions restrictions on resources often mean that entitlements based on rights are denied and needs are not met (Munford and Bennie, 2009).

For many families/whanau adequate 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 and training and supporting workers. The provision of support is likely to be variable and in rural and isolated areas the choices are restricted. Moreover families/whanau often need to do a lot of work themselves to locate appropriate support and often speak of their disquiet when they have to work with organisations to assert their rights for care. 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; Munford, 1994b; Munford et al., 1994). For these families/whanau locating appropriate support is not a seamless process and while the Disability Strategy may emphasise their key role in supporting their family/whanau members and their own right to support, in reality this may not be the situation for them. The major challenge is to translate policy guidelines into realistic options for families/whanau and to develop processes that enable families/whanau to easily access support. Despite the challenges there are some excellent examples of practice where disabled people and their family/whanau are at the centre of the support process. These support services uphold the philosophy that

support should be tailored to the needs of the person and the vision that guides this practice is to support the person to live in the community of their choice with the right supports that enable them to fully participate in this community.

Keeping a strengths focus and achieving a sense of coherence

Given the daily challenges they face families/whanau may struggle to maintain a focus on the positive experiences in their daily lives. Support workers can encourage families/whanau to find the strengths within their family/whanau and their wider network but at times it can be difficult for families to keep 'body and soul together'. For many families/whanau achieving a sense of coherence and meaning about their situation can be immensely difficult as they work to achieve the daily practical tasks that support requires. It can be immensely challenging to manage the needs of all family/whanau members and at times factors external to the family/whanau can put added pressure on family life. A significant pressure that can undermine their sense of wellbeing is being able to manage the way 'difference' is defined. Discourses about family/whanau life that construct and define the experiences of disabled people in terms of deficits can place immense emotional pressure on the family/whanau. Despite the important achievements at the policy level the daily experiences of families are often imbued with an added struggle 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/whanau as they need to deal with others' interpretations of their family/whanau life. They feel that their private experiences become open to a public gaze and their experiences are the focus of unwanted attention that is not only unhelpful but can be demeaning. The kindly advice given by well meaning outsiders can often undermine their confidence to care well. Such responses can also function to restrict understanding of the family/whanau as all family experiences are constructed from one perspective and other aspects of family/whanau life, such as the needs and aspirations of all family/whanau members can be ignored (Munford et al., 1994).

The strengths perspective pushes us to think differently about family/whanau life and to understand that a focus on deficits and problems can mask the 'multiple positions' families may occupy (Munford and Sanders, 2005; Sanders and Munford 2010). While not denying the challenges and the daily struggles that families/whanau may

face, families/whanau also want recognition of the diversity of family/whanau life; their experiences of disability is one aspect of family/whanau 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.

Valuing the support relationship

Many families/whanau speak of the devaluing of the support relationship both in terms of a failure to recognise it as an important activity and its central role in supporting disabled people to be included in community life and also in terms with regard to how the identities of those involved in support are constructed. Those outside the support relationship may perceive the support role as a burden and this undermines the importance of this relationship and also devalues the identities of those within the relationship. The Disability Strategy highlights valuing of individuals as one key aspect of inclusion and as a foundation for a rights approach where all individuals have the right to be protected and included. Portraying the support relationship as a burden can undermine the potential of this relationship to offer opportunities for both partners in this relationship. What families/whanau 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. A definition of the support relationship as a burden fails to capture the reciprocal nature of the relationship and what it is each partner contributes to this relationship. Moreover, these definitions can reinforce the historical perceptions of disabled people as passive victims that require protection and are unable to be active in decisions about their lives (Munford 1994a, 1994b).

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 and as a relationship that is part of the natural fabric of community life. The support relationship is meaningful for both partners and while it has unique challenges, with the appropriate resources the needs and rights of both partners can be promoted. It is useful to define what is happening in the support relationship and to have family/whanau members and those they support define what this relationship means

to them as this can bring further understanding of the challenges but also the potential this relationship holds for full participation in community life. Care by family/whanau 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/whanau support has relational, affective and behavioural aspects and it is constituted of 'labour and love' and of 'activity and identity' (ibid, p. 7). Support in the family/whanau takes place in a relational context of commitment and attachment and a range of support is provided, including emotional, practical and financial (ibid, p. 7). Support provided by family/whanau is a complex and important activity that has a central role in implementing the key vision statements of the Disability Strategy that uphold disabled people's rights to live in valued relationships and access networks of support within their local communities. Of significance is building an understanding of how this relationship may change over time as new needs emerge. Regardless of what needs emerge this relationship will remain as a central relationship in a disabled person's life journey. All members of this support relationship should be respected, valued and supported and there must be acknowledgement of its key role in supporting people to have full and meaningful everyday experiences.

Working with the professionals

While we may define support provided by family/whanau as informal care and different from formal care that is provided by qualified people in a professional capacity (Collings, 2009, p. 7) the tasks that are carried out by family/whanau can be complex and require a high level of skill. This support role is enduring over time and is present throughout the key developmental phases of a disabled person's life. The family/whanau needs to understand and respond appropriately to the developmental changes in the disabled person's life cycle and context and take on multiple roles ranging from emotional to practical support. Some professionals fail to recognise the complexity of the role and do not acknowledge the knowledge, skills, and expertise the family/whanau develops over time. While some families/whanau feel very supported in their role and are acknowledged for what they have contributed, others feel that professionals only see them as providing emotional support and do not recognise the skills they have in the other areas of care, such as developing communication skills, working on enhancing mobility, managing medication and

clinical routines, and helping the disabled person work through identity issues. While many families/whanau would willingly have others complete these tasks, this kind of support is often unavailable so it rests on families/whanau to equip themselves with the knowledge and skills to effectively support their family/whanau member. Given this experience, family/whanau 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/whanau 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. If family/whanau support is perceived as a valued societal activity and as central to advancing the wellbeing of disabled people, it follows that families/whanau should be involved in key decision-making processes about support and service provision (Munford, 1994b). Ideally all of those involved in providing support to a disabled person are viewed as an interdependent team; this approach is a key theme of the Disability Strategy. Here the disabled person is at the centre of an interdependent network whose members' knowledge and skills are equally valued and where they are all recognised as having something positive to contribute.

Consistency of support – working with family/whanau meaning systems

Consistency of support takes many forms; a primary concern is having a consistent approach to supporting the disabled person so that there is no disruption to the quality of support provided. This includes ensuring that added pressure is not placed on the family/whanau because they are needing to take time out to advocate and argue for resources or are expected to cope with constant changes in service delivery including turnover of staff. They may be asked to brief and support new staff and through this process are constantly asked to tell their story and explain their circumstances. Many families/whanau talk of having to cope with the added pressures of changes to service delivery systems; 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 the 'goal posts have shifted'.

Consistency of support also means that service organisations understand support within the context of family/whanau life including the meaning systems and cultural frameworks of the family/whanau. In Aotearoa New Zealand this means understanding the diversity of family/whanau life and the bicultural (Maori and non-Maori) and the multicultural (Pacific Islands populations, migrants and new settlers, and refugees) fabric of our society. Support takes place within an already established framework of family/whanau life and understanding this can enable professionals to more effectively support families/whanau. Families/whanau tell us that professionals will be unable to form genuine and authentic relationships with clients if they do not recognise the diversity of family/whanau life. This includes understanding how the family's/whanau meaning systems and values determine the nature of the support relationships within that family/whanau and who is to be involved in this support; for example, understanding the role of family/whanau members in the wider family/whanau network as both providers and recipients of support.

Being available to care

Many families/whanau talk about needing to have support to enable them to care and to achieve wellbeing for themselves and their family member. They report that the right networks can enable them to sustain support over a long period and to maintain their sense of coherence; respite care is one key aspect of this. Family/whanau also report that the stress they may experience can be misinterpreted as an unwillingness to do this role when in fact other factors are impacting on the support role. Our research on families/whanau has demonstrated that there may be factors that prevent families/whanau from being able to parent not because they do not desire to do so but these factors can be overwhelming and disrupt family/whanau relationships (Munford and Sanders, 2005, p. 169). These are not 'failed' families but are families who are under stress for a range of reasons including *inter alia* ill-health; poverty, intra-personal issues such as their own wellbeing issues emerging from challenges in their family history; and intergenerational issues such as care being required across generations.

To be able to care families/whanau need to be available and professionals can do much to support them to be available. Practical strategies such as respite care and ensuring that families/whanau are not isolated from support networks in their own
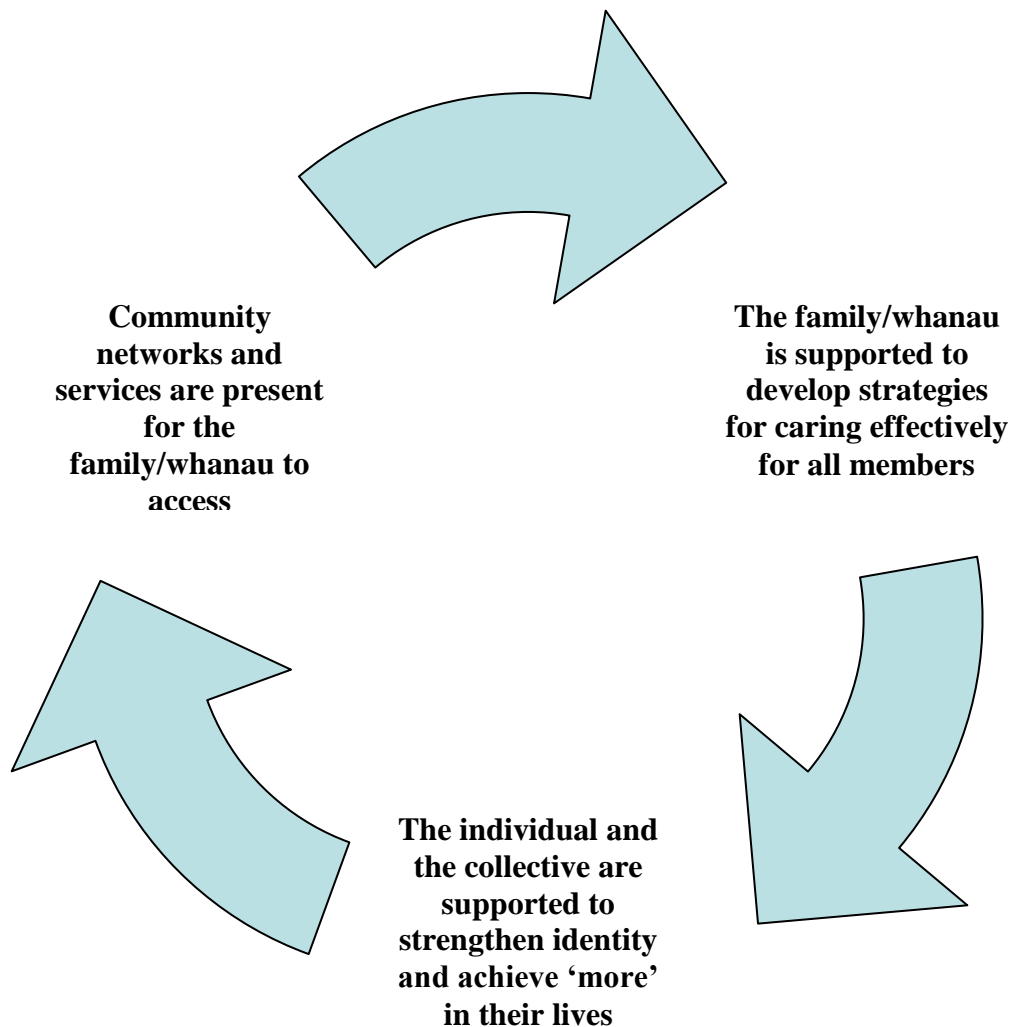
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communities will assist them as will recognising the value of the other roles they perform in their family/whanau and external to the family/whanau. Assisting families/whanau to be involved in a range of experiences contributes to their own wellbeing and supports them to achieve a sense of mastery (Collings, 2009, p. 7). Associated with this is supporting families/whanau to be able to attribute positive regard to the support role and to understand the dynamic interplay between 'caring about' someone and also 'caring for' someone. Those families/whanau whose self-identity is constructed positively as a family/whanau caregiver are more likely to accept support (ibid, p 7) and consequently as their needs are being met both emotionally and practically they are more likely to be available to care.

This discussion above has outlined a number of key themes that are present in the lives of families/whanau; these may create challenges for them as they mediate their caregiving role with other factors in their family/whanau life. The next section presents a range of the strategies for building strengths and resilience in family/whanau life.

Making a Difference – What Works

This discussion focuses on three areas. Based on an ecological- transactional approach effective support for families/whanau and those they support is perceived as an integrated system that focuses on the interaction between the family/whanau, the individual and the community which includes both formal organisations and informal networks 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/Whanau, Community and Individual Strengths and Resilience

Community networks and services are present for the family/whanau to access

The family/whanau is supported to develop strategies for caring effectively for all members

The individual and the collective are supported to strengthen identity and achieve 'more' in their lives

The Family/Whanau

Understanding strengths and capacities – changing our perspective

A strengths approach assists us to think differently about family life; to move from a focus on 'problems' and 'deficits' to thinking about what it is that can positively

influence family/whanau life. A focus on strengths does not ignore risks or issues but encourages us to find solutions by seeing and thinking differently about family/whanau life (Munford and Sanders, 2008; Munford et al., 2012; Sanders and Munford, 2010). A key focus is to determine how families/whanau 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/whanau possess strengths and resources that can be harnessed in support processes.

- An understanding that professionals need to invest in building effective relationships with families/whanau so that they can assist in harnessing strengths and resources.

- That labelling families/whanau as dysfunctional when they are not coping can mean that we do not learn and understand how families/whanau 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 professionals need to think about what it is that enables families/whanau to survive and grow and to understand that service systems can actually alienate families/whanau and make it more difficult for them to locate support.

- That requiring formal support reinforces our interdependence as community members and should be perceived as a natural component of the fabric of community life.

- That professionals need to be creative in assisting families/whanau to find solutions and obtain support and know how to work on multiple levels and collaboratively with other professionals and service systems to ensure that practical and emotional needs can be met.

Underpinning strengths approaches is the belief that all families/whanau 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. What is more helpful for families/whanau is to develop an understanding that focuses on how we can support

them to identify the strategies that will make a real difference in their daily lives (Munford and Sanders, 2010).

Understanding context

Understanding context includes learning how political, social, economic, religious and cultural factors influence family/whanau 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 and Tsui, 2010; Houston, 2010). Professionals who fully understand the contexts of family/whanau life can assist them to find opportunities; central to this is developing an understanding of the frameworks families/whanau use to make sense of their worlds including cultural, religious and spiritual beliefs. Families/whanau 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 professionals challenge themselves to reflect on their own contexts and how these prepare them for working with families/whanau. This includes engaging in honest reflection on how much they know about the family's/whanau context and the communities in which they live. Do they understand the nature of community life and whether these communities are part of the network of support for the family/whanau or function to further marginalise and isolate families/whanau (Munford and Sanders, 2008)? Also of interest is the agency context and thinking about how this impacts on families/whanau including assessing whether the agency enhances or hinders interactions with families/whanau. A key question here is: is the agency able to be in partnership with families/whanau to challenge services systems that exclude families/whanau and disabled people? Part of this process may include facilitating processes that will support families/whanau to challenge structures and systems that prevent them from accessing support including the natural supports within their communities.

Harnessing natural supports

Families/whanau and the person they support 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/whanau are not 'blank slates' or the passive recipients of wisdom bestowed upon them by experts (Sanders and Munford, 2010, p. 38). Families/whanau know what has not worked for them in the past and they are the bearers of their own unique histories. They have come to agencies to find support in their support role not to have their knowledge and expertise devalued. When professionals enter a family's/whanau 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/whanau 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/whanau life and it is the family/whanau who will be in charge of decision-making and the implementation of these decisions.

As Gilligan (2004) asserts professionals need to be aware of their own strengths and they need to understand that they are not the exclusive source of help. Successful work will occur when professionals understand the social contexts of clients' lives and know how to support them to harness the strengths within these contexts (ibid, pp. 101-2). The view of the family/whanau at the centre is the foundation of the thinking behind a 'whanau ora' approach where the whanau directs the care and support that is required and that the support that is provided incorporates the meaning systems of the whanau and works with these to bring about positive change for the whanau (Ministry of Social Development, 2010).

Building resilience and capacity

Building resilience and capacity are key factors in determining how families/whanau can sustain support over the long term including being able to achieve wellbeing for all family/whanau members. Understanding how resilience can be developed is at the core of successful support as it captures understanding about how families/whanau and the people they support can develop coherent meaning systems and strategies that enable them to maintain a sense of control over their lives. Being able to develop resilience and capacity means that they can live meaningful lives and can work with support systems to determine their support needs and can take control of how they

want these to work for them. They are able to assert their rights as citizens to be included and to fully participate in their communities.

Professionals can have key roles in supporting families/whanau to develop resilience and build capacity. Their role may be to help families/whanau understand how their strategies in providing support are building resilience and how the strategies they have developed in the support role can be harnessed to address future challenges; for example, learning to work with education officials to ensure that their family/whanau member is able to attend their local school. The strategies developed here can be used to address other issues and it also draws other people into the family's/whanau network of support.

An ecological perspective on resilience foregrounds the interaction of key systems and their role in contributing to a family's/whanau and individual's resilience (Liebenberg and Ungar, 2009). Resilience is a function of the social ecology of an individual or family/whanau wherein environmental, cultural and social resources can create pathways for positive growth. Viewed in this way resilience is not seen to be an individual attribute but arises out of the interaction between individual factors and the social environment (Liebenberg and Ungar, 2009. Families/whanau 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 (ibid). For example, a family/whanau 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 these resources to match the specific needs of the family/whanau. If the family/whanau 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/whanau may need to be supported to use them effectively. The whanau ora approach is an excellent illustration of the way in which resilience works within a social ecological approach. Whanau ora shifts attention from individuals to collectives; it is about wellness, health and resilience for the whole whanau. Those working within such an approach seek resources within social and cultural contexts and networks in order to achieve self-determination and to

attain and maintain wellness for all members of the family/whanau (Ministry of Social Development, 2010).

Building resilience is a complex process and at times it will be the unexpected or unpredictable events that will enable the family/whanau and their family/whanau member to experience success. Being open to new possibilities and sources of support can strengthen a family's/whanau support network and build capacity over time. Professionals can be helpful by working to find multiple options of support including exploring the natural networks available for support. To be effective support systems for the family/whanau need to be acceptable and meaningful for the family/whanau and not disrupt family/whanau life and the routines and processes they have established.

The Individual

Reciprocity

As discussed in preceding sections our understandings about impairment and disability have changed over time and policy statements such as the Disability Strategy provide guidelines for thinking about how services and support for disabled people can be effective and open up possibilities for their current lived experiences and for the future. Disabled people remind us that the provision of care and support happens within a relationship and that to be meaningful this relationship should be based on reciprocity (Munford et al., 1994; Munford 1994a; Munford 1994b). Traditional conceptions of the provision of care viewed the person with the impairment as needing protection; they were passive in the care relationship having things done to them not with them.

Building a reciprocal relationship when one partner is the 'cared for' can be difficult and it requires considered attention so that both partners feel they gain something from this relationship. Many families/whanau report that the support relationship can be troubled when they themselves do not receive the support they need (Collings, 2009). While the support tasks can be challenging they can cope with these and find reward in the relationship if they receive support including access to respite care. For the person receiving the support access to respite care and time out from the ongoing support relationship enables them to 'try out' different connections with others and

develop their systems of support. When family/whanau and those they support become isolated from other support systems care experiences can feel like a burden and reciprocity will be difficult to achieve. The family/whanau member being supported can feel that they have little to give back to the family/whanau and that their support needs have consumed all of the family's/whanau emotional and physical resources. A key role of support from outside of the family/whanau is to broaden the range of experiences of all family/whanau members; this support builds opportunities for the family/whanau member receiving support to build a positive identity through building new relationships where they have opportunities to give back to others.

Constructing positive identities

Disabled people's 'difference' has over time been devalued and they have been unable to find valued positions in their community and fully participate in community life. In recent times these constructions of 'difference' have been challenged and policy and practice now emphasises the celebration of diversity and the support of the goals and aspirations of disabled people. While these claims are laudable for things to change in practice disabled people must be supported to find ways to construct positive identities and feel supported to do so. This requires a commitment to interdependence and others taking the time to understand the barriers to inclusion and working with the person to overcome these.

The support relationship is critical in assisting the person to develop a positive identity. The psycho-social support provided needs to be respectful and the person receiving support needs to feel they have control over the decisions being made about the support they will receive. While the disabled person may need to have many of their daily care tasks carried out for them the support worker needs to learn how they can support the person to construct a sense of coherence and control over their situation. The key role of a support worker is to provide the person they support with the opportunity to make choices about their support and to 'try out' other activities and experiences. An effective support worker understands the restrictions of the impairment and the impact on the daily life of the disabled person. They also understand how the social, political, economic and physical environments can function to further restrict opportunities. A key role is to assist the disabled person to find ways to mediate these influences and take some control back, and build self

efficacy in order to construct a sense of self and a meaningful identity. Again this requires creativity as like the family/whanau who is attempting to build resilience and capacity so is the disabled person and opportunities may be found in unexpected places. Building contacts with others outside the family/whanau may enable the disabled person to develop other aspects of their identity. A positive identity is constructed within meaningful relationships and these relationships can offer up new possibilities.

Finding possibilities – creating 'more'

As the preceding discussion illustrates disabled people have often been restricted in the choices they can 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 work is informed by 'possibility thinking' or finding 'more' for the person to experience (Handley at 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/whanau and individuals in the past and using these to open up new possibilities for the future (ibid). It moves from a focus on coping with a situation to taking control of a situation and also using the success in addressing current issues to build strategies for dealing with issues in the future.

'Possibility thinking' requires professionals 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 person to seek 'more' and to have big dreams and to envision different futures. While providing appropriate support for a person 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/whanau? Support can have a key role in advancing community participation and inclusion and it can extend opportunities and possibilities for growth. The support relationships that are formed are not just about responding to immediate needs but can enable the disabled person and their family/whanau to have new experiences that seed other opportunities, expand their vision and generate the confidence to seek out new possibilities for the future.

The Community

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 and that an important long term goal is to develop an interdependent network of support that will enable families/whanau to seek out a range of options for support (Merriman and Canavan, 2007; New Zealand Carers Alliance, 2007). Successful support options acknowledge the diversity of family/whanau life and experiences and incorporate these into decision-making and short and long term planning. Families/whanau will experience conflicted feelings when seeking support and these must be recognised and acknowledged; both their needs and rights and those of the disabled person must be responded to sensitively and respectfully. Seeking help is not easy to do and so it is important that engagement with services is seen as part of the package of support families/whanau can expect to receive.

The challenge for support services is to be both person-centred and family/whanau centred so that the needs of both the disabled person and the /whanau inform decisions about the way support will be provided (Merriman and Canavan, 2007). As Merriman and Canavan (2007) suggest, services should be designed in partnership with families as they have expertise and the knowledge and understanding of their family/whanau member. Those planning services need to find ways to develop collaborative partnerships with families/whanau and their family/whanau member so that their knowledge and ideas inform planning processes both in terms of what they specifically require for their family/whanau and in the design of support services in general.

Collaborative practice

In the provision of support from agencies the family/whanau must always remain at the centre and must have a key role in determining what support systems will be effective for them and their family/whanau member. It is important that helping relationships do not undermine a family's/whanau efficacy and their ability to care. Relationships with professionals should not add to family/whanau stress; these relationships should add value to family/whanau life and should not represent another

challenge the family/whanau is required to mediate. Approaching families/whanau with respect for their expertise and competence provides a strong base upon which a collaborative partnership can be built. Working collaboratively aligns with approaches that are concerned with enhancing participation and citizen engagement in decision-making. Active participation of the family/whanau in decision-making about support work is critical to its success.

Collaborative 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 and Munford, 2010). 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/whanau and disabled people bring to the planning table; alliances with families/whanau and disabled people should be culturally responsive and respectful of differing meaning systems. Working collaboratively and in partnership with families/whanau enables professionals to support families/whanau to identify what has worked for them in the past and to 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.

Building Collaborative Support Partnerships – the family/whanau and disabled person is at the centre of the network of support

At the centre of effective support for disabled people and their families/whanau are collaborative partnerships. This term defines the way engagement with both formal services and informal networks should work in practice. Effective services are built around the regular and normal routines of family/whanau life and as with the whanau ora approach they take a whole family/whanau perspective on providing support. Providing support to a family member is viewed as an expected part of family/whanau life and by providing effective and responsive support the health and wellbeing of the

whole whanau is enhanced. This orientation to providing support is a taken-for-granted expectation of family/whanau life; not something that happens only when families/whanau are in crisis and under immense stress. This means that families/whanau can make the most of support and build it into their repertoire of resources that enable all family members to achieve health and wellbeing. This approach gives effect to the vision of creating nurturing and inclusive communities. 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/whanau so that all family/whanau members can experience wellbeing. The way to achieve this is for professionals to develop collaborative practice and form authentic and respectful relationships with families/whanau that enhance their coping skills and build long term strategies for enhancing family/whanau life.

The key elements of collaborative support partnerships are:

- The disabled person and their family/whanau are at the centre of the support partnership and determine the nature of the relationship with professionals and service systems.

- A family's/whanau cultural frameworks and meaning systems are respected and inform the way in which the support partnership is enacted. Generating connections with cultural meaning systems can assist the family/whanau 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.

- Collaborative support partnerships are based upon an understanding of the way in which context influences family/whanau and community life. This involves understanding how political, social, economic, religious and cultural factors influence and shape what it is possible for families/whanau to achieve. Here there is an acknowledgement of how effective support relationships can support families/whanau and disabled people 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.

- Natural networks of support are harnessed through the family/whanau. The support partnership should not disrupt the natural coping mechanisms that have been developed by the family/whanau and should build upon what has already been established within the family/whanau.

- The needs of all family/whanau are considered in the support process and like the whanau ora approach the focus moves from an individual problem orientation to a collective response. Here the focus is on the whole whanau in order to achieve the goals and aspirations of all whanau members. In this communal approach to wellbeing the focus is on whanau wellbeing and self-determination where intergenerational knowledge, values and resources are shared in order to gain full participation of the whanau in community life.

- A key element of collaborative support partnerships is the sharing of diverse knowledge. Based on the key concept of Ako from Maori pedagogy (Munford et al., 2012) this orientation to the provision of support 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 the support relationship are respectful learning relationships. This idea is closely related to the notion of reciprocity where both partners in the support relationship give and receive from one another. Such an approach also embraces the idea of mutuality and ecological interdependence which creates connections and solidarity between people who are all striving to learn how to adapt and transform their environments. It unleashes the propensity for growth through shared learning; in this way both the person being supported and the person providing support are mutual learners in a process that enables them to acquire knowledge and skills that will enhance the support relationship. Given the knowledge and skills they have developed over time disabled people and their families/whanau can help professionals learn about what constitutes effective support. The idea of shared learning disrupts the notion of dependency on services and invokes the notion of interdependence and the idea that inclusion in community life requires a change in thinking about support and service relationships where disabled people are not recipients of service but are in control of the way in which services are provided to them and their support networks.

- Central to collaborative support partnerships is the provision of integrated services that enable the disabled person and their family/whanau to enter into relationships with service systems that are themselves integrated and collaborative. Here service systems are prepared to engage differently with their communities and to work in partnership with other professionals to ensure that service provision is responsive and does not create barriers that disrupt the achievement of successful support relationships. This may require that professionals 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 the support relationship.

- Collaborative support partnerships will respond to the immediate and practical needs of a disabled person and their family/whanau but have the potential to contribute to strengthening a family's/whanau support network in the long term and are a mechanism for opening up opportunities for inclusion and participation. The principle of 'more' and 'possibility thinking' (Munford et al., 2012) constructs the support relationship as an opportunity for the disabled person and their family/whanau to engage in transformational change where visions and aspirations can be achieved. A collaborative support 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.

- The realisation of collaborative support partnerships requires ongoing critical reflection (Munford et al., 2012). Here the disabled person and their family/whanau create mutually agreed processes that enable all partners in the relationship to reflect on the partnership. Such processes are an integral component of the support partnership; they require an 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 paper has identified some of the factors that contribute to supporting families/whanau to build strengths and resilience. It began with providing a discussion on the historical influences on the construction of disability and support and on the provision of services. While the focus is on Aotearoa New Zealand the experiences in this country mirror those internationally. 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/whanau life as historically families/whanau were encouraged to move their /whanau members to large segregated institutions and had little or even no contact with them. The move to community-based services resulted in a change in role for families/whanau as they took on the major caregiving role and the support of their family/whanau member. To do this successfully they became experts in a range of areas and learned how to be strong advocates for their family/whanau member so they could gain access to appropriate support and services.

The second section picked up the issues for families/whanau as they work to provide effective support to their family/whanau member. Informal family/whanau based care is focused on an enduring relationship and families/whanau have become experts in 'caring for' their family/whanau member while maintaining other family/whanau relationships and routines. Of significance is how family/whanau members can be supported to sustain care over a long period while maintaining there own health and wellbeing. The third section outlined a number of key factors that contribute to effective care and support. This section was concerned with the interests and roles of families/whanau, the individuals receiving care and community responses to service provision and support. The idea of collaborative support partnerships was proposed as one approach to providing effective support as it keeps the family/whanau and the disabled person at the centre of decision-making and takes a collaborative approach to service planning and provision. Such programmes also have the potential to advance the interests of disabled people and their /whanau by encouraging interdependence and contributing to the inclusion and participation of disabled people in their

communities. Collaborative support partnerships open up possibilities for disabled people and their family/whanau to dream for 'more' for their future. Here the provision of support is a central component of service delivery where those charged with developing these kinds of services recognise that the act of receiving and providing support within a nurturing relationship can support the family/whanau and their family/whanau member to build strengths and resilience that will contribute positively to their future health and wellbeing.

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