

# Rethinking Respite Policy for People With Intellectual and Developmental Disabilities

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**Abstract** Respite care is one of a range of support services typically available to carers of people with dependencies who need a break from caring, and the factors that influence the need for respite care are generally similar irrespective of the nature of the dependencies. Hence, the expectations of families potentially have policy and service provision implications regardless of the jurisdiction. However, there is considerable variability in the provision of services, not only between jurisdictions, with differing levels of service development, but also within jurisdictions. The history of disjointed service provision suggests the need for a rethink of respite policy. The authors discuss the conceptual framework and prevalent thinking on respite policy such as a shared understanding of respite care among stakeholders. In turn, this shared understanding is seen as generating a move toward integrated service development, recasting respite as part of a continuum of family support services in which funding policies give families more control. The authors conclude that respite care provided in an integrated framework moves beyond the basic function of a break in caring to one of supporting family coping and resilience.

**Keywords:** carers, family, intellectual disabilities, policy, respite

## INTRODUCTION

Respite is well researched in the area of intellectual and developmental disabilities (Chan, 2008a; Chan & Sigafoos, 2000, 2001; Cramer & Carlin, 2008; McConkey, Kelly, Mannan, & Craig, 2010; Merriman & Canavan, 2007; Olsen & Maslin-Prothero, 2001; Ridley, Chan, & Roberts, 2004) in aged care and mental health (Jeon, Brodaty, & Chesterton, 2005; Jeon, Chenoweth, & McIntosh, 2007; Perry & Bontinen, 2001) and, more recently, in the area of acquired brain injury (Chan, 2007, 2008b). While there is a general agreement on the need for respite services for people with disability and their family carers, the availability of and access to a flexible range of respite services continue to be problematic for many people (Brown, McWilliam, Westmore, Keast, & Schmidt, 2000; Chan, 2007, 2008b; Cramer & Carlin, 2008; Hughes, 2007; Jeon et al., 2007; McConkey et al., 2010; Merriman & Canavan, 2007; National Family Carers Voice, 2004; Spicer, 2007). Respite appears to be more difficult to access for family carers who have children with complex healthcare needs (Robinson, Jackson, & Townsley, 2001), for older carers of people with severe mental illness (Jeon et al., 2007), for both children and adults with acquired brain injury (Chan, 2007, 2008b; Pickelsimer et al., 2007; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007),

for chronically ill older people (Brown et al., 2000), and for people with lifelong disability (Hughes, 2007; Spicer, 2007).

The original purpose of respite care was to allow carers a break from the pressure and responsibility of full-time caring, thereby enabling people with intellectual disabilities to stay at home (Cotterill, Hayes, Flynn, & Sloper, 1997). The rationale for giving carers a break in the short term was that they were more likely to continue to care for their family member full time in the long term (Chesson & Westwood, 2004). This could postpone or even eliminate the need for residential care for service users and can keep families together longer (Cotterill et al., 1997). However, where service provision including respite is irregular and unreliable, it may ultimately lead to out-of-home placements when families reach a breaking point (Chan, Sigafoos, Watego, & Potter, 2001; Koloski & Montgomery, 1995). As such, planned early intervention respite is one way of enabling families to continue the care at home (Cummins, 2001), rather than as a crisis response (National Family Carers Voice, 2004).

There are also common factors that may influence the demand for respite regardless of disability types (Chan, 2007, 2008a, 2008b; Chan & Sigafoos, 2000; Chesson & Westwood, 2004; Cotterill et al., 1997; McNally, Ben-Shlomo, & Newman, 1999). Some of the consistent factors found in the developmental disabilities, acquired brain injury, mental health, and aged care literature include individual factors such as the severity of challenging behavior, the severity of the disability, and the level of dependency of the person on the carer (Chan, 2007, 2008a, 2008b) as well as family factors such as the stress level of the family carer, family structure (including marital breakdown and

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lone parents), and the desire to have a “normal” life (Nankervis, Rosewarne, & Vasos, 2011). Hence, regardless of disability groups and jurisdictions, the needs for respite as articulated by family carers are similar, and these views are important in terms of how respite policy ought to be reframed and implemented.

Respite is central to disability and mental health policy because it has consistently shown positive effects on family functioning (Chan & Sigafoos, 2001; Cotterill et al., 1997; MacDonald & Callery, 2004). The natural family of the service user has an opportunity to do something other than care for its family member (Chan & Sigafoos, 2001). Families choose to spend this time in a range of ways, including household work, spending time with other family members, and sleeping (Merriman & Canavan, 2007). There are also possible benefits for service users, particularly derived from host family respite or holiday breaks, including their involvement in another family’s life and experience of activities in which they might not otherwise participate (McConkey & McCullough, 2006; Merriman & Canavan, 2007).

Herman and Marcenko (1997) suggested that when access to respite is problematic or when the interaction with the staff is difficult, use of the respite services may use up more time and energy leading to more rather than less stress for the family. Therefore, it is important to ensure that obtaining access to respite should not be a stressful experience for carers. Family carers need to feel confident and stress free when trying to organize respite. This means that the entire experience of accessing respite should be stress free from the moment a carer thinks he or she needs respite to when respite is provided and completed. Furthermore, family carers already experience feelings of guilt when accessing respite that adds to their stress (Damiani, Rosenbaum, Swinton, & Russel, 2004; Neufeld, Query, & Drummond, 2001; Ridley et al., 2004), therefore an aim of respite should be reducing family stress and guilt by providing an integrated practice that supports the family carer and family cohesion.

The ideal of community care is that people with intellectual disability would live a full, inclusive life nurtured by those around them (Quin & Redmond, 1999). In a community care model, families assumed the duties of care, with the support of the community. Furthermore, there are strong arguments for the social and economic benefits to governments through the provision of care and support provided within the family (Cummins, 2001; Jeon et al., 2007; National Family Carers Voice, 2004; Post, 2007). The economic benefits for government include substantial savings in funding (Cummins, 2001; Post, 2007). Cummins (2001) argued that while there is an increasing trend toward encouraging family care for people with disability, there is minimal corresponding concern in supporting families who care for the family member with a disability at home. He also proposed that increased public expenditure needs to be directed to the care of people with severe disabilities.

Given the benefit that governments potentially derive from families continuing the care and support to persons with a disability in the family home, it is critical for a government-led policy of not only meeting unmet needs but to lead fresh thinking of how respite service can achieve target outcomes and improve family resiliency. Respite will not serve its intended purpose and achieve the potential outcomes if there is the continuing failure to address the needs of people with disability and their family carers (Chan, 2007, 2008b; MacDonald & Callery, 2004). As such, respite

provision must meet the needs of families and promote a shared understanding of care (Chan & Sigafoos, 2001; Jeon et al., 2007; MacDonald & Callery, 2004).

Respite has consistently shown benefits for service users and their families, as indicated in this brief review and more thoroughly elsewhere (e.g., Chan & Sigafoos, 2001). However, disjointed implementation of and lack of coherency in respite policy has hampered the consistent availability of respite care and limited its positive effects. This article presents an argument for a model of service delivery that builds on a shared understanding of respite among stakeholders, on integrated service provision, and on a person-centered funding model. While policy contexts vary, the principles informing this model can be applied to any new policy on respite care.

#### SHARED UNDERSTANDING OF RESPITE

An important point to consider when trying to define respite care is that the answer often depends on who is asked. For example, parents, nurses, and social workers in one study differed widely in their definitions of respite and expectations about services (MacDonald & Callery, 2004). Parents all had different answers depending on their family circumstances; services which parents called respite, nurses may call baby-sitting; and while parents and nurses favored out-of-home respite, social workers disagreed with use of out-of-home respite. Provision of respite care requires understanding of the meaning of respite for stakeholders and a negotiation of these sometimes opposing points of view (MacDonald & Callery, 2004). This section focuses on the similarities in the experiences of a range of service users and their families, without denying the differences in their cases but using the similarities as a starting point in developing policy.

Throughout the literature on respite, family carers have voiced their need for accessible information regarding respite and that such information is an important starting point in their consideration of respite (Chan, 2007, 2008b; Cotterill et al., 1997; Jeon et al., 2007; McConkey, 2005). Indeed, McConkey (2005) has argued that while respite is an important service for the person, it may not be widely known and accessed. Information needs to consist not only of the availability and accessibility of respite but also what types of respite are available (such as in-home respite or holiday camps) and how convenient it is for carers to contact the respite service provider. Information should not only be in print media but also could be in various formats, such as audio and computer web-based systems. Information ought to be available in a range of local and community services settings. Accessible information needs to consider the needs of diverse cultural, religious, and linguistic groups (Cotterill et al., 1997; Niemeier & Arango-Lasprilla, 2007). People from diverse cultural and linguistic backgrounds may not necessarily be able to navigate the complex social services system (Montoro-Rodriguez, Koloski, & Montgomery, 2003). However, from the point of view of the service providers, advertising and awareness-raising may lead to increased demand for services when providers are often unable to meet existing demand.

Jeon et al. (2007) examined how older carers of people with a severe mental illness access respite in New South Wales, Australia. They found that respite service provision needs to involve a

concerted effort of carers, health professionals, and service providers. They recommended better information system and coordination of services for families and for respite services to be flexible and appropriate to the population they serve. This finding reiterates similar results found in previous research in various disability groups and in different jurisdictions (Chan & Sigafoos, 2000; Chiu, Tang, Shyu, & Chang, 1999; Damiani et al., 2004; Kersten, McLellan, George, Mullee, & Smith, 2001; Neufeld et al., 2001). That is, there are many family needs that are similar in relation to respite services despite the differences of respite service delivery in various jurisdictions.

Families who use respite consider it important that respite service providers have staff who have the appropriate training and learning development. Respite service providers also share this view. For example, people with acquired brain injury have strongly indicated the importance of having trained and qualified staff or volunteers (82%) and recruiting appropriately trained staff and volunteers (81%) (Chan, 2008b). Similarly, families have also reported as important their expectations of recruiting trained staff and volunteers (85.9%) and having trained and qualified staff and volunteers (82.4%) (Chan, 2007). Respite providers have also reported similar expectations in recruiting and having trained staff and volunteers (Chan, 2008a). Having trained and qualified staff can provide carers and people with disabilities with the confidence about the quality of the respite service and the knowledge of the quality of staff and volunteers can be a welcome relief from the stress derived that carers may be leaving the responsibility of care of the person with disability with the respite service (Chan & Sigafoos, 2001).

In summary, different stakeholders have differing conceptualizations of respite, its purpose, and its intended benefits. Communication and information sharing among stakeholders is important to develop a shared understanding of respite. Based on this shared understanding, training can be provided for service providers to ensure that high standards of care, as high as those provided by family carers, can be achieved. When a high standard of care can be expected by family carers, the confidence and trust they place in service providers also increases. However, these changes cannot occur if respite care is considered separate from other elements of service provision and policy for people with disabilities.

## INTEGRATED SERVICE DELIVERY

Respite potentially acts as a buffer against the demands of caring for a person with a disability and families' needs to fulfil their responsibilities. Respite needs to be viewed along a continuum of support services that builds family resilience and coping (Dowse, Gill, Webb, & Moore, 2003; McCubbin & McCubbin, 1996; Merriman & Canavan, 2007). This also means considering carers and persons with a disability as partners in the continuum of support—by assisting in a family's adaptation and coping to presenting stressors in the family (McCubbin & McCubbin, 1996). Such an approach in policy direction where care and support are seen as a partnership potentially removes both the burden of care and the stigma of that burden from the family. In such a partnership, respite is thus seen as part of build-

ing on family resources and social networks (Brown, 2007; Dowse et al., 2003), and there is mutual benefit for the family and government.

The next decision is whether services administration should be central or local. For new respite care programs, the question is whether there is strict central control of its delivery by service providers or whether there is flexibility at local level to adapt the model to meet the unique demands of population density or other such variables. This is related to the question of the formality and bureaucracy of the administration of services. More formal services with higher demands on providers to certify their suitability and to report to families and to the state, as required under the Care Standards Act (Department of Health, 2000) in Great Britain, represent moving away from the community care model.

An integrated service provision views respite as not simply an isolated episode in a family's life and time as a break from caring but places it along a continuum of support services that builds community connectedness (Merriman & Canavan, 2007). In this context, respite is seen as part of a responsive and quality social support system that seeks to restore and regenerate family well-being and resilience; where care and support become a positive experience for the carer and person; and hence scaffolds positive family adaptation. This model translates policy implications into practice and service delivery; that is, there is a significant shift from a burden-of-care model to a positive caregiver-care recipient relationship, where care and support is a partnership with the provider and aligned with government policy.

Using an integrated respite practice-oriented framework (Montoro-Rodriguez et al., 2003), Chan (2007, 2008b) offered suggestions for training required by respite staff. First, carers and respite providers have identified the level of challenging behavior as influencing respite use (Chan, 2007, 2008a). Chan and Sigafoos (2000) also found that the level of challenging behaviors is a significant predictor of respite use. As such, it is appropriate that respite practitioners are provided training in how to support persons presenting with challenging behaviors and to be able to implement behavior support programs across various settings. There are ample behavior support training programs in the disability literature that respite providers can access. Addressing the level of challenging behavior may potentially alleviate the stress of carers who will view such training and skill of staff as an additional competency to their overall qualifications.

Second, stress-related factors were reported by families and respite providers to influence respite (Chan, 2007, 2008a; Chan & Sigafoos, 2001). Hence, to alleviate stress and promote well-being is important and as such, respite practitioners should be afforded training in how to support and respond to the stress of family carers. Training should not be limited to simply dealing with the stress produced by the person with the disability (or derived from the carer) but to provide an atmosphere of well-being in the respite service. Such a model that aims to alleviate the stress of family carers and promote well-being builds on the idea of harnessing the altruism of carers and promoting the "joy of caring" (Maarbjerg & Bundgaard, 2006) and the shared understanding of care and support exemplified in family support services.

Third, training specific to the psychosocial and healthcare needs of persons with disability is recommended. Training needs to consider the impact of disability on the individual and family

TABLE 1

Principles of best practice in the provision of respite care

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|------------------|--|
| Principle one:   | That respite services be person centered and family centered.  |
| Principle two:   | That respite services be provided on a rights basis.   |
| Principle three: | That respite be defined as a support service and regarded among a system of support services.                            |
| Principle four:  | That there be a single point of access to respite care services in a given administrative area.                          |
| Principle five:  | That respite services be designed in consultation with families in acknowledgement of their expertise in providing care. |
| Principle six:   | That respite be designed to facilitate the service user in building relationships in their community.                    |
| Principle seven: | That respite services be age appropriate and develop as the service user develops.                                       |
| Principle eight: | That respite care services have clear goals and that systematic and regular review ensure achievement of those goals.    |

Source: Merriman and Canavan (2007).

carers and their unmet needs (such as the importance of community integration and being able to respond to the mental health needs of family carers and persons with a disability). Development of specific training for staff need not be the primary responsibility of respite providers. It is reasonable for respite providers to link their training requirements to existing education and training services.

Building on existing research knowledge about respite and its effects, there is a need to measure the benefits of respite for family carers and persons with disabilities over time to assess the effect of different types of respite services and the quality of the respite service being delivered. More importantly, further research on the nature of the relationship between carers and service users, the quality of life outcomes, and benefits that family carers and persons with disability derive from respite services is warranted in order to inform policy, resource allocation, and practice. Such research should not only be focused on the measurement of stress reduction for the carer but also (a) on the general health and well-being of the carer, the person with disability, and the family unit using quality of life measures; (b) on family resilience as measured by family coping capacity and cohesiveness; (c) on the degree of community integration of the person with a disability; and (d) the benefits that may be derived from caring (Brown, 2007). In general, more high quality respite-focused research studies that allow for meta-analysis would provide significant quantitative supplement to the predominantly qualitative and narrative review of research (Chan & Sigafoos, 2001). This additional knowledge would allow for the examination of discrete effects on particular demographic groups or of particular disabilities. To better examine the long-term effects of respite, longitudinal research is required, which can better inform policy direction and strategic planning of respite service provision. Such information is important in terms of planning and resource allocation, determining priority of access, setting eligibility criteria, and assisting in management decision making to determine equity of access to respite. The role of research in service development, then, is a means of monitoring and evaluating services.

Respite as part of integrated service provision can play a part in facilitating family resilience and regenerate families' internal strength and internal locus of control, that is, to focus on family time, routines, and well-being in the face of disability as a stressor

(McCubbin & McCubbin, 1996). Merriman and Canavan (2007) outlined several provisional principles of best practice in respite service provision: respite should be person and family centered, should be based on rights, should be considered as part of a continuum of support services, and should have a single point of entry (Table 1). Integrated respite service provision is thus seen as a community resource available to the family that views them as partners in the shared care and support that builds upon the family's own personal resources. The family carer's personal resources include the skills and knowledge acquired from education and training and well-being that draws upon the positive aspects of caring; these can create better adaptation to the stressors associated with disability (McCubbin & McCubbin, 1996). In this context, respite is seen as part of a responsive and quality social support system that seeks to restore and regenerate family well-being and resilience, where care and support become a positive experience for the carer and person, and hence scaffolds positive family adaptation. Fully functioning, integrated social services would include all social, medical, and paramedical services, designed with the input of all stakeholders and be fully integrated and responsive to the changing needs of service users and families over time. This model translates policy implications into practice and service delivery and signals a significant shift from a burden of caring model to a positive caregiver-care recipient relationship and where care and support is a partnership with the provider and aligned with government policy.

#### FUNDING RESPITE

Another element of a shared understanding of care and support is to provide families control of and ownership in how services are delivered, particularly when such ownership potentially leads to higher service satisfaction and less stress experienced when accessing respite (Caldwell & Heller, 2003; Chan & Sigafoos, 2001). Furthermore, family carers and persons with disability are seen as proactive participants in addressing their needs, rather than passive recipients of respite and support. Such a concept builds on the family's strengths and well-being that in turn can facilitate family resilience in the face of disability as a stressor (McCubbin & McCubbin, 1996). A pilot program in the

United States gave service users (“consumers”) control over the entire budget for their care (Caldwell & Heller, 2003). Carers tended to hire friends, neighbors, and members of their extended families (Caldwell & Heller, 2003). Families with more control over services in this way were generally more satisfied with the level of service. Other consequences of the scheme were greater involvement of the service user in the community and increased employment of carers (Caldwell & Heller, 2003).

According to the Australian Institute of Health and Welfare (2007) report, funding for respite across Australia makes up 8% (\$A196.7 million) of the total national budget for disability services (\$A3.6 billion) for the period 2004–2005 (Australian Institute of Health and Welfare, 2007). In the same period, the number who accessed respite increased from 9,141 to 11,103 people across 709 respite service outlets (Australian Institute of Health and Welfare, 2007). Despite the increase in the number of people accessing respite and an increase in its funding in the same period, respite continues to be an unmet need with 53% of people who used respite reliant on informal unpaid carers to fulfill the role of support and caregiving (Australian Institute of Health and Welfare, 2011). A more recent report indicated that expenditure on respite has the largest number of increases (77%) from 2004 to 2009 compared with services such as accommodation, employment, or community access (Australian Institute of Health and Welfare, 2011). In Ireland, 5,472 people were in receipt of respite services (21% of people with disabilities) and a further 3,740 (14.3%) require new or enhanced respite services in the period 2010–2014 (Kelly, Craig, & Kelly, 2010). In Ireland, the Health Service Executive uses baseline unit costs to determine the allocation of formal out-of-home respite services. For 2007, the unit cost of a residential place was €80,000 (€219.18 per night) and of a respite place was €80,000 (€219.18 per night) (T. McGuirk, personal communication, March 8, 2007). Costs of home sharing, a model of out-of-home respite, ranged from €12.70 to €66.00 per night (Hanrahan, 2004).

Families already incur increased expenditures related to the disability and also face the financial strain of caring (Hughes, 2007; Spicer, 2007). The lack of money and the expenses incurred as a result of caring are stressors for families (Douglas & Spellacy, 2000; Hughes, 2007). To circumvent such stressors, a consideration of government policy could include a subsidy for those families who may not be able to afford a full fee-for-service respite. The potential of such a scheme is that it will encourage families to seek or purchase respite when required. Government subsidy for respite may generate interests in the nongovernment sector such as local community support groups or charities to increase the capacity and availability of respite, particularly in rural and regional areas. The Irish government offers a grant to the families of people with disabilities to procure respite services, for example, in the form of holiday breaks (Daisychain Foundation, 2006). A similar scheme operates in Great Britain and, with the growth of nonstatutory agencies providing care services, the Care Standards Act (Department of Health, 2000) was passed to regulate this burgeoning sector.

Funding flexibility is proposed so that families can use available funding in a way that best suits the needs of the person and his or her carer, giving them more control instead of relying on service providers. For example, it is appropriate for a family carer to use the flexible respite funding to pay for an air fare of a family

member or a friend to care for the person at home rather than accessing out-of-home respite. Funding portability provides the opportunity to expend the respite funding to another geographical area (Ridley et al., 2004). Consistent with the social model, the benefits of such an informal respite include the fact that the family carer is confident of the care being provided because it is someone the carer trusts, it potentially reduces the stress for carer and the person as the care is being provided in a familiar environment, and it also provides a vacancy in the out-of-home respite for another family who may require it. Flexible funding also allows families to save their respite allocation when they might need it most. For example, it allows carers to seek employment or meet their employment requirements, undertake personal development such as further studies, or when other family events require their participation. Hence, the family carer continues the rhythm of life routines and maintains a locus of control to cope with a potential stressor (McCubbin & McCubbin, 1996).

Funding flexibility and portability also introduces another potential innovative feature of banking the allocated respite hours to when respite is most needed by the family carer. Instead of an allocated time and date for respite, the carer may choose to bank or save the respite hours. This concept also allows the family to use respite when it is most required or suitable rather than be controlled by an allocated respite date and time. It provides the family greater flexibility to manage his or her schedule. Control of the funding by family carers may lead to greater service satisfaction (Caldwell & Heller, 2003; Chan & Sigafos, 2001; Ridley et al., 2004). Family-directed or consumer-controlled service provision is also associated to greater community involvement by the person with a disability (Caldwell & Heller, 2003). Hence, funding portability and flexibility provides for greater locus of control for the family carer and potentially more beneficial.

## DISCUSSION

Policy on services for people with disabilities is at a stage of transition in a number of jurisdictions that offers an opportunity to refine and enhance the delivery of services, including respite care. There are several policy and service delivery implications for respite provision outlined in this article. The social model of disability emphasizes the shared role of the family and the state in caring for people with disabilities. Respite care is conceptualized here as one element of a continuum of integrated services along which the responsibility of caring is distributed. In order to achieve a balance at each point on the continuum, a shared understanding of respite care, and of services in general, is required. The shared understanding is the foundation for the training, communication, funding flexibility, and mutual trust among stakeholders. In this way, respite can become much more than just a break for overburdened carers of people with disabilities. There are social and economic gains to be achieved from such a shared understanding as family already contribute significantly to the care and support of the person with a disability in the family home. As such, these families need support and respite needs to be seen in the continuum of family support, and caring for the person with disability is no longer perceived as a burden.

Integrated service delivery requires the cooperation of the service user and their family, service providers, the staff of service

providers, and the state. The barriers to accessing respite occur between these stakeholders and, following directly from the arguments for the importance of a shared understanding of respite care, recommendations are made here for staff training. Qualified and appropriately trained staff and volunteers play a critical role in enhancing the notion of an integrated respite service provision, where family carers and persons with disability are seen as customers so that they can feel confident when using respite. Respite staff and volunteers need to be adequately trained to implement programs and interventions devised by psychologists or other therapists, such as supporting individuals with challenging behaviors. It is important to measure the outcomes derived from respite provision to enable measurement of the benefits of respite and how to allocate resource appropriately and promptly. Furthermore, building on existing research on the impact of respite care, we would propose the instigation of a longitudinal study of people with disabilities.

Another area of service provision that might merit further research is funding. Respite funding flexibility has potential and merit in policy development as it can be individualized to the needs of family carers and persons with disability. Respite ought not to be viewed as simply an isolated episode in family's life and time as a break from caring. Respite needs to be responsive to the needs of family carers and persons with a disability and where respite service provision acts as a quality social support system that enhances family well-being and resilience. Accessible and readily available information is seen as an important first step as carers who need such a service but are often unaware that respite exists.

From examination of policy contexts in Australia and Ireland, it is clear that the interplay between disability-specific policies and the more general thrust of social and economic policy means that policy implementation varies considerably from country to country. Based on this conclusion, it may appear that caution should be exercised in applying disability respite policies across national boundaries. This article has identified elements of policy, service delivery, and funding that can inform national policy and facilitate the transfer of research findings beyond their original setting.

A model of integrated service delivery is available that can extend the benefits of respite to more service users and families. This requires a common understanding of respite's purposes and intended benefits among stakeholders as well as flexibility in service provision, as in the example of funding. The flexibility of the model extends to the range of its application: variation in policy contexts means that service providers and service users face different challenges, but the principles underlying the model can still inform their decision making and planning to make for the optimal use and maximal benefit from respite care.

## REFERENCES

- Australian Institute of Health and Welfare. (2007). *Current and future demand for specialist disability services*. Canberra, Australia: AIHW.
- Australian Institute of Health and Welfare. (2011). *Disability support services 2008-09: Report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement*. Canberra, Australia: AIHW.
- Brown, S. L. (2007). Health effects of caregiving. *Alzheimer's Care Today*, 8, 235-246.
- Brown, J. B., McWilliam, C., Wetmore, S., Keast, D., & Schmidt, G. (2000). Is respite care available for chronically ill seniors? *Canadian Family Physician*, 46, 1793-1800.
- Caldwell, J., & Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research*, 47, 352-366.
- Chan, J. (2007). Carers' perspective on respite for persons with acquired brain injury. *International Journal of Rehabilitation Research*, 30, 137-146.
- Chan, J. (2008a). A profile of respite providers in New South Wales. *International Journal of Disability, Development & Education*, 55, 289-302.
- Chan, J. (2008b). What do people with acquired brain injury think about respite? *International Journal of Rehabilitation Research*, 31, 3-11.
- Chan, J. B., & Sigafos, J. (2000). A review of child and family characteristics related to the use of respite care in developmental disability services. *Child & Youth Care Forum*, 29, 27-37.
- Chan, J., & Sigafos, J. (2001). Does respite care reduce parental stress in families with developmentally disabled children? *Child & Youth Care Forum*, 30, 253-263.
- Chan, J. B., Sigafos, J., Watego, N., & Potter, G. (2001). Adults with intellectual disability in long-term respite care: A qualitative study. *Journal of Intellectual & Developmental Disability*, 26, 339-344.
- Chesson, R. A., & Westwood, C. E. (2004). *Making a break: Developing methods for measuring the impact of respite services*. Aberdeen: Shared Care Scotland.
- Chiu, L., Tang, K. Y., Shyu, W. C., & Chang, T. P. (1999). The willingness of families caring for victims of stroke to pay for in-home respite care: Results of a pilot study in Taiwan. *Health Policy*, 46, 239-254.
- Cotterill, L., Hayes, L., Flynn, M., & Sloper, P. (1997). Reviewing respite services: Some lessons from the literature. *Disability & Society*, 12, 775-788.
- Cramer, H., & Carlin, J. (2008). Family-based short breaks (Respite) for disabled children: Results from the Fourth National Study. *British Journal of Social Work*, 38, 1060-1075.
- Cummins, R. A. (2001). The subjective well-being of people caring for a family member with a severe disability at home: A review. *Journal of Intellectual & Developmental Disability*, 26, 83-100.
- Daisychain Foundation. (2006). *Time for you programme*. Retrieved from [http://www.daisychainfoundation.org/time\\_for\\_you.htm](http://www.daisychainfoundation.org/time_for_you.htm)
- Damiani, G., Rosenbaum, P., Swinton, M., & Russell, D. (2004). Frequency and determinants of formal respite use among caregivers of children with cerebral palsy in Ontario. *Child: Care, Health & Development*, 30, 77-86.
- Department of Health. (2000). *Care standards act*. London: Stationery Office.
- Douglas, J. M., & Spellacy, F. J. (2000). Correlates of depression in adults with severe traumatic brain injury and their carers. *Brain Injury*, 14, 71-88.
- Dowse, L., Gill, M., Webb, L., & Moore, S. (2003). *The way forward: Supporting parents across NSW—Strengthening the partnership with the disability sector*. Sydney: Carers NSW.
- Hanrahan, D. (2004). *National home sharing network: Directory of services*. Drumcar, Ireland: Author.
- Herman, S. E., & Marcenko, M. O. (1997). Perceptions of services and resources as mediators of depression among parents of children with developmental disabilities. *Mental Retardation*, 35, 458-467.
- Hughes, J. (2007). Caring for carers: The financial strain of caring. *Family Matters*, 76, 32-33.
- Jeon, S. H., Brodaty, H., & Chesterton, J. (2005). Respite care for caregivers and people with severe mental illness: Literature review. *Journal of Advanced Nursing*, 49, 297-306.

- Jeon, S. H., Chenoweth, L., & McIntosh, H. (2007). Factors influencing the use and provision of respite care services for older families of people with a severe mental illness. *International Journal of Mental Health Nursing, 16*, 96–107.
- Kelly, C., Craig, S., & Kelly, F. (2010). *Annual report of the National Disability Database Committee 2009*. Dublin: Health Research Board.
- Kersten, P., McLellan, L., George, S., Mullee, M. A., & Smith, J. A. E. (2001). Needs of carers of severely disabled people: Are they identified and met adequately? *Health and Social Care in the Community, 9*, 235–243.
- Koloski, K., & Montgomery, R. J. V. (1995). The impact of respite use on nursing home placement. *The Gerontologist, 35*, 67–74.
- Maarbjerg, A. W., & Bundgaard, K. (2006, September 27). *Unconditional approach to citizens, center for short breaks, Vejle County*. Workshop best practices case presented at the 4th Quality Conference 2006 “Building Sustainable Quality,” Tampere, Finland.
- MacDonald, H., & Callery, P. (2004). Different meanings of respite: A study of parents, nurses, and social workers caring for children with complex needs. *Child: Care, Health & Development, 30*, 279–288.
- McConkey, R. (2005). Fair shares? Supporting families caring for adult persons with intellectual disabilities. *Journal of Intellectual Disability Research, 49*, 600–612.
- McConkey, R., & McCullough, J. (2006). Holiday breaks for adults with intellectual disabilities living with older carers. *Journal of Social Work, 6*, 65–79.
- McConkey, R., Kelly, F., Mannan, H., & Craig, S. (2010). Inequalities in respite service provision: Insights from a national, longitudinal study of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 23*, 85–94.
- McCubbin, M. A., & McCubbin, H. I. (1996). Resiliency in families: A conceptual model of family adjustment and adaptation in response to stress and crises. In H. I. McCubbin, A. I. Thompson, & M. A. McCubbin (Eds.), *Family assessment: Resiliency, coping and adaptation* (pp. 1–64). Madison, WI: University of Wisconsin Publications.
- McNally, S., Ben-Shlomo, Y., & Newman, S. (1999). The effects of respite care on informal carers’ well-being: A systematic review. *Disability and Rehabilitation, 21*, 1–12.
- Merriman, B., & Canavan, J. (2007). *Towards best practice in the provision of respite services for people with intellectual disabilities and autism*. Galway, Ireland: Child and Family Research Centre, National University of Ireland.
- Montoro-Rodriguez, J., Koloski, K., & Montgomery, R. J. V. (2003). Evaluating a practice-oriented service model to increase the use of respite services among minorities and rural caregivers. *The Gerontologist, 43*, 916–924.
- Niemeier, J., & Arango-Lasprilla, J. C. (2007). Toward improved rehabilitation services for ethnically diverse survivors of traumatic brain injury. *Journal of Head Trauma Rehabilitation, 23*, 75–84.
- Neufeld, S. M., Query, B., & Drummond, J. E. (2001). Respite care users who have children with chronic conditions: Are they getting a break? *Journal of Pediatric Nursing, 16*, 234–244.
- Olsen, R., & Maslin-Prothero, P. (2001). Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs: Evidence from an evaluation. *Journal of Advanced Nursing, 34*, 603–610.
- Perry, J., & Bontinen, K. (2001). Caregivers described how an Alzheimer’s disease respite programme gave them time to attend to their own needs. *Canadian Journal of Nursing Research, 33*, 81–95.
- Pickelsimer, E.E., Selassie, A.W., Sample, P.L., Heinemann, A.W., Gu, J.K., & Veldheer, L.C. (2007). Unmet service needs of persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 22*, 1–13.
- Post, S. G. (2007). Stumbling on joy: Not always a “burden” of care. *Alzheimer’s Care Today, 8*, 247–250.
- Quin, S., & Redmond, B. (1999). Moving from needs to rights: Social policy for people with disability in Ireland. In S. Quin, P. Kennedy, A. Matthews, & G. Kiely (Eds.), *Contemporary Irish social policy* (pp. 146–169). Dublin: University College Dublin Press.
- Ridley, G., Chan, J., & Roberts, J. M. A. (2004). *Appropriate and effective models of respite care for children under 7 years with disability and for children with disability and challenging behaviour or high medical support needs*. Sydney: Centre for Developmental Disability Studies.
- Robinson, C., Jackson, P., & Townsley, R. (2001). Short breaks for families caring for a disabled child with complex health needs. *Child and Family Social Work, 6*, 67–75.
- Rotondi, A. J., Sinkule, J., Balzer, K., Harris, J., & Moldovan, R. (2007). A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *Journal of Head Trauma Rehabilitation, 22*, 14–25.
- Spicer, I. (2007). Disability and family carers. *Family Matters, 76*, 30–31.