

Re-Thinking Respite

By John Armstrong & Lynda Shevellar

Social Role Valorization provides a framework for upgrading the social status of people at risk of devaluation and even those already devalued. This article examines one particular service model – the traditional respite service model – to assess the ways the potential for valued roles is facilitated or impeded, and what steps might be taken to increase the chances that children especially, but also their parents might receive the benefits that valued social roles may bring.

“Families with a child who has a disability or chronic illness know the commitment and intensity of care necessary for their children. The level of dedication and care becomes part of daily life, part of the family routine, but this same commitment can make stress routine too... It is obvious to anyone who has lived this life that respite care becomes a vital service – a necessity, not a luxury” (National Information Center for Children and Youth with Disabilities, 1996)

The “Need” for Respite Care

The “need” for respite care is generally uncontested. Respite is commonly regarded as a necessity and indeed is often described as a “right”. This paper seeks to explore the Respite Service Model as being one of *the* most dominant and expanding service models available to children and families. In this exploration, we are not seeking to critique specific respite services, nor to question the very genuine struggle that families experience, as articulated in the above quote. Rather we seek to explore the assumptions underpinning the model that such service responses rest upon. Whilst our analysis is drawn from working with and evaluating respite services in Australia, we suspect that these trends are consistent amongst other Western countries. Researchers note that there is an increasing demand for even greater levels of respite care to be provided by governments around the world (Pearson & Moore 2001). With increasing demand comes increasing expectations. This paper asks whether it is possible for the respite model to bring the benefits that most of us have to come to expect from it. Moreover, could it be possible that the respite model exacerbates the very problems it is designed to remedy, for the parents as well as their son or daughter?

“Respite” is a term that at first seems clear but has a number of subtle meanings. It shifts from respite as use of time, to respite as a geographical location. The Respite Review Report defines respite as a "desired outcome of an intervention" and "a description of those alternative care arrangements that are funded and provided as one way to produce the desired outcome for carers" (1996, p. 40). Pearson and Moore (2001) see it as simultaneously meeting two policy goals: to provide support to carers; and to prevent or delay admission to residential care. At a more practical level, Ingram (n.d.) suggests that “respite” refers to short term, temporary care provided to people with disabilities to provide relief to families from the daily routine of care-giving. Referring to it as “the gift of time”, she suggests that one of the important purposes of the respite model is to give

family members time and to temporarily relieve the stress they may experience while providing extra care for a son or daughter with a disability. Respite services also operate within the aged care arena, providing similar assistance to people who care for their parents, or spouses. Ingram also supports the notion that this “relief” helps prevent abuse and neglect, and supports family unity.

The features of such services vary enormously, however the dominant versions at present include day centres, overnight care for an extended period of time or occasionally in-home assistance (which may also include shorter outings). The shared feature is a response to the question “Who takes care of the caregivers?” (National Information Center for Children and Youth with Disabilities 1996).

People immersed in a culture tend towards uncritically embracing that culture. It is not surprising to find some families who become enveloped in a human service system, simultaneously growing more isolated from the wider culture. Such families will “need” and seek more of those things that the human service system has to provide. This need arises from many reasons that include:

- few service arrangements that really advance people’s circumstances;
- a poor array of service options – especially for adults with disabilities;
- respite being a familiar and historically valid response;
- a school system that most often poorly prepares children for adulthood and adult and work roles;
- “post school options” for adults that provide few real community roles, skills or associations;
- political imperatives that encourage the development of particular solutions to community issues that unintentionally lock devalued people out of valued roles and into negative or devalued roles;
- economic imperatives that encourage congregate models of care;
- low expectations for disabled adults generally; and
- in the face of such systemic inadequacies a call to provide more respite to alleviate the “needs” of families.

Certainly, the severe nature of many family circumstances exacerbated by systemic dysfunctionality leads parents to reach out for what is often the only presented “solution”: namely, respite. Families with members who have disabilities experience the absence of appropriate financial, emotional, physical and social supports. These difficulties are heightened as parents become older. For example, Queensland Parents of People with a Disability (QPPD 1989) reveals the following comments by parents:

- “He goes to the nursing home in the next town for a holiday. That’s very expensive and hardly a holiday”
- “No one will take her for respite because of her special diet”
- “I can never do anything spontaneous. Any respite has to be planned weeks ahead”
- “All I have for respite now is a trip to the local hospital for a couple of weeks”

- “It’s so undignified asking for help. I virtually had to slash my wrists and drop blood all over their desks before the administration would give me respite”

It is assumed that a break will deliver much needed rest and refreshment, especially in the presence of an incoherent service system, that the parents will have become strengthened and ready to take on the challenges of the returning family member. However, evidence suggests that rather than strengthen parents, it may actually reinforce the necessity for such periods of respite at increasing intervals and duration¹. McNally, Ben-Shlomo and Newman (1999) reported “29 studies from which there was little evidence that respite intervention has either a consistent or enduring benefit on carers well being.” (cited by Pearson et al p.12). Like an addictive drug, respite is both an expression of things not being quite right while also being the panacea for it.

Many parents and people with disabilities are highly conscious of the limitations of the respite model, but struggle with the lack of alternatives, or the lack of flexibility in how funding might be used. The prospect of placing a family member with strangers, or being placed in particular environments, creates a dilemma, and even dread:

“I don’t like the idea of a respite care bed in their house with a different person coming to stay every week. That’s not a normal home life!” (QPPD, 1989, p. 61).

“I have respite in (a nursing home). I dread it every year. It’s like doing a term in prison” (QPPD, 1989, p. 61).

Implications of the Respite Model

If the respite model was actually renewing it should enable parents to *better* deal with the support issues of their son or daughter. Instead what it typically reinforces is how much families “need more respite”, in an ever increasing cycle of escalating “need”. Why is this the case? Why do parents who receive respite need even more? Why can it still end with permanent residential care as is evident from anecdotal experience (which respite is supposed to prevent or delay) for a son or daughter? And most importantly, is there any other way around this? Setting aside the issue of “rights to respite” and other entitlement perspectives, let us look at what respite is commonly like.

SRV helps in distinguishing between what a need is, versus how to meet it. It is a common error to confuse these two aspects and can cloud ones thinking about how to best meet someone’s needs, if you have *already* determined how it should be met. For example, no one needs ‘respite’ – not even parents. What they may need is rest, recover, re-energising, and inspiration. They may also need a way of hanging onto their valued roles and to remain part of a wider community. If we define their needs as the service, i.e., ‘respite’ we have already closed off the possibility of exploring other things that would really meet these needs.

¹ Whilst some studies do show parents being highly *satisfied* with their respite service this is a different question as to the long-term impacts of respite services.

The respite model physically and/or socially separates one party out for the benefit of another. In other words the primary recipient of respite – the family² – receives an *indirect* service; the secondary recipient: the son or daughter receives a *direct* service. By removing the person or exchanging the “care giver”, the primary purpose of respite has been attained. Nothing more need be expected – except more of it! The interests of the primary recipient party (the family) have been served. What happens to the person once they are removed is *not* the essential or primary concern. The focus is on the removal and/or separation of one party to affect a “break” for another.

Another important SRV related construct is whether a service is *relevant* to the person(s) being served. Relevance requires that there is a precise match between what a person needs and what they get. This of course assumes that the service recipients needs have been correctly appraised and how urgent or exaggerated those needs are, and what response is suitable or relevant. If a service is irrelevant, then the persons needs will be exacerbated to some extent, even to the point that the service becomes damaging because of the mismatch between what they need, and what they receive. This article here is looking at the potential of such a mismatch in a respite care context and what that might produce.

Consequently, respite becomes a passive service form. By passive, we mean a service response that is at the same time concerned about time (away from the family), but also not concerned about time (how the time of the removed person is occupied). This is because the respite model, even when it is regularly and repeatedly provided, is often an immediate short-term response to a longer-term difficulty within a family, but which does not address that difficulty. Thus, not only is respite passive, it is a short-term remedy applied repeatedly – sometimes for a very long time, even decades – with little or no remediating effect on the family structure. In short, it is a solution that does not actually address the fundamental problem.

Passivity is further demonstrated when sons and daughters receive activities, outings, trips to places like shopping malls, movies, television, picnics and the like, or confinement in facilities which of themselves *appear* benign enough but are largely irrelevant and wasteful to an adult future, and especially so because it is endlessly repeated. The other people in the respite program which one does this with, who may be *very* diverse in age, ability and compatibility can reduce even further the potential of doing something for the service clients that contributes to a beneficial future.

The respite model also raises problems in relation to its purview. Our assumption is that services should be developing competencies – assisting people to learn and grow.

Most competency or ‘function contingent’ roles (cook, mechanic, economist, home owner etc) require competencies to perform them. Thus a major SRV related strategy – also in common with many other approaches – is the developmental growth orientation a service will require if it is to successfully facilitate people’s development into valued social roles.

² Many agencies are aware of the tension between the interests of one party over another and intend to ensure that the child’s interests are represented or even focussed on. Our point here is that there *is* a tension between what are often competing and even opposing interests.

However if the respite model is utilised, the opportunity for developing competencies is reduced because the influence on a person's life *appears* to be so small. Yet the cumulative effect of years of non-growth oriented respite is devastating.

If the culturally valued analogue (CVA) for respite is one of "holiday", it may be argued that respite provides "rest and relaxation" to people with disabilities, in much the same way as people without disabilities look forward to holiday time.

The *Culturally Valued Analogue* (CVA) comes up a lot in SRV because it relates to the way a service effort would operate if it was provided to valued people. Such a handy construct provides insight into how those types of needs would typically be met, how growth would be facilitated and how images about people would be enhanced. In other words, the CVA is a handy benchmark for a service to compare its activities against and to ask whether one is doing anything that violates their CVA, and what might be done about it. Violation of a CVA runs the risk of failing to meet people's needs, looking strange against the wider culture and therefore damaging the image of service recipients. Violating the CVA (as in a prominent example like an institution) can also lead staff to think that strange practices are warranted and can overlook or excuse how bizarre things may have become.

Within this CVA a reduced purview may therefore be appropriate. There are however a number of important considerations. Firstly, rest and relaxation are appreciated in contrast to a hectic and demanding life. For many people with disabilities the dilemma is more one of a lack of busyness and the need for meaningful activity rather than a need for yet more rest. Secondly, such an approach denies the multitude of forms that a holiday can take. For many people recreation may also take the form of learning ("Let's travel overseas"), pursuing interests ("I want to get to the artist's retreat this year"), setting goals ("At last I can re-paint the kitchen") and taking on new roles ("I can't wait to become a gym-member again"). For some people holidays actually require a greater expenditure of energy and provide a rich range of experiences and roles. For people with disabilities experiencing the respite model, particularly centre-based respite, there is often simply the continuation of the role of client and the opportunity to continue doing little within a new location. Judith McGill asserts that given the isolation and lack of community integration for many people with disabilities, and the importance of developing strong identities, there is a compelling need for more active, person-centred, community based recreation, rather than yet more passive leisure time (Hutchinson & McGill 1998; McGill 1996).

A Change in the Nature of Parent/Child Relationship

Respite can start for one reason but continue for another. Parents normatively become more exhausted the more isolated they are. But desperation and competition for scarce support can draw a parent into a cycle of exaggerating demand where their "needs" for respite have to escalate. Sometimes collective action by parents also reinforces this claim by interpreting the need for respite as a "Right"³. This is further reinforced by a broader societal trend (at least within Australia) to present oneself as pathetic as possible in order

³ Recently in Australia, one example of collective action claimed that 'carers' saved \$30 billion a year for the government, implying that such care *should* have been provided by government anyway and that the current arrangement of 'unpaid care' provided by parents netted the government a very significant saving!

to be “eligible” for a particular service or payment. In our experience, this arrangement can foster and promote an unhelpful role dynamic.

SRV utilises what is known (from social science) about how valued and devalued roles operate so as to affect the formation of positive perceptions about the people we know and support. This section examines the interplay of roles between people so that a conscious use of this interplay can be used for positive advantage.

We know that many roles occur as complementary to another person’s role (Newcomb, Turner & Converse 1975; Lemay 1999). This complementarity of roles is a healthy and normative part of our society and occurs in everyday circumstances, such as the roles of parent and child, doctor and patient, employer and employee, or teacher and student. However, a negative interdependency of roles (Berne, 1961; Berne 1964) can also be constructed, such as the roles of addict and supplier. This interplay of roles and expectations is often unconscious and results from a range of subtle social dynamics. It is never the result of just one person’s actions, but is based on interdependency and interaction that serve to encourage and reinforce each other’s roles.

How the Service Interaction Can Facilitate Further Changes

The respite model of service can create a “drama triangle” (Karpman 1968) wherein the role of a parent seeking greater amounts of respite can have a negative effect on their son or daughter’s role. In the absence of informal supports, the family seeks increasing amounts of formalised arrangements to rescue them from this difficulty. The parent may enter the Victim⁴ role – either unconsciously constructing him or herself as a Victim, or being constructed into the role by others. The son or daughter is then identified as the “cause” of the difficulty, and is thus cast into the devalued role of Burden.

For example, one of the things we know from social science is that anyone can descend into negative roles quicker and easier than ascend into positive roles. We also know that this is especially powerful if certain (often devalued) people have little or no access to valued roles and fill their *deep* need for a role with even a small role or relatively insignificant feature, or even an entirely negative role. This section examines how that might be possible not only for a disabled son or daughter – but also a parent, and how service interactions could facilitate or strengthen such a process. Of course it would be best if this descent into negative roles were avoided altogether.

The Victim role is more secure the more its contrasting and (negative) complementary role of Burden is demonstrated. Thus the more difficult a child is presented to be, the more convincing the parent’s plight. As Victim, the parent is demonstrated to be more deserving of greater paid intervention. The following passage illustrates the construction of the parent as Victim vividly:

⁴ The Victim role is an “attractive” negative role to many people: it often engenders sympathy from others, it reduces personal responsibility for a circumstance, and may make one eligible for various services. And yet like many negative roles it can entrap the incumbent. The Victim role becomes less attractive over time to others who tire of the interaction with the Victim, and so the role may produce withdrawal, despair and even anger from other parties.

“[A]n increasing number of families are finding it tougher to deal with a catastrophic illness or a family member with a disability. The insidious thing about all this it has been like a rising evening tide, not a tidal wave, so it has caught us out, and it has caught individual families out, and many times we do not hear with clarity the pleas for help, and we do not often understand the magnitude of the problems we are dealing with” (Botsman 2000).

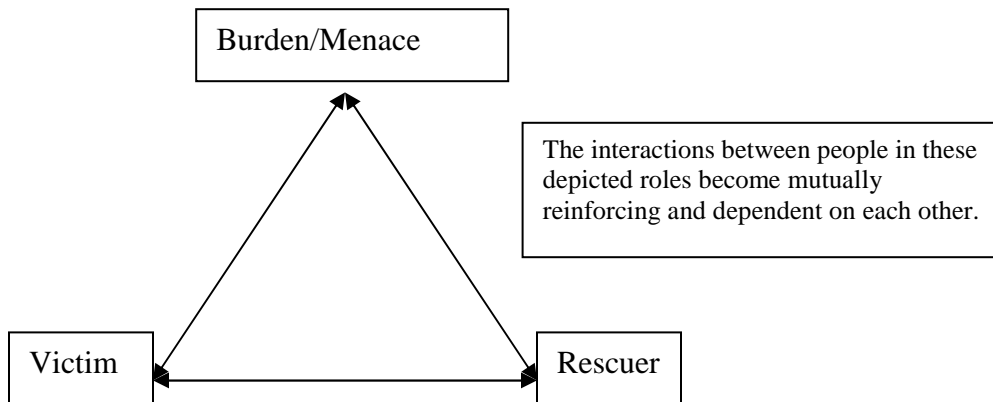
The drama triangle is a potentially very damaging dynamic, as the roles can shift and intensify over time. For example, in Australia, the growth in “managing challenging behaviour” has seen people with disabilities “multiply in deviancies” (Wolfensberger, Wounds presentation) from the Burden role to also acquire the Menace role. As both parents and their children grow older, there is also increasing evidence of people with disabilities entrapped in the Eternal Child role, or being given the role of already aged or sick with respite models based in Hospitals, Nursing Homes or Senior Citizens centres.

Families may indeed be burdened by the social situation they find themselves in. However, this private experience is very different from the public construction of their loved one *as a burden*. Over time, the burden role can even be internalised by the person, as the following quote from a young woman with multiple disabilities illustrates:

“I feel trapped. I’m just between the same two walls all the time. Mum and Dad get sick of me. I’m always in the road. I feel I’m just a pest. They are always having to worry about me” (QPPD, 1989, p. 61)

Third parties, such as Respite Services and their personnel, can reinforce this drama triangle by providing “emergency” aid, thus adopting the role of Rescuer. This is especially so if the agency and workers subtly emphasise and reinforce how difficult living with this person must be. For some conditions (for example, dementia and acquired brain injury) it is common to see workers identify much more closely with the “carers” than with the impaired person. The service feels and becomes indispensable to the Victims’ circumstances and stops questioning the arrangement as it become internally reinforcing between all three parties. For example, Disability Services Queensland proclaims, “Respite services play a *critical role* in keeping families together” (2004, added emphasis).

Psychological theory (Corey 1991) suggests that this interplay represents a power struggle with the Rescuer (often unconsciously) working to keep others in a dependent position, whilst over time some Victims may grow to resent and even persecute the Rescuer. As the dynamic escalates, the service may begin to construct *itself* as the Victim of the family creating resentment towards the family or the person with a disability declaring them no longer eligible for service or referring them onto other agencies “who can meet their needs”.



The Victim role will become especially enlarged if there are few other roles in the parent’s life – especially those of a more normative nature: spouse, worker, colleague, neighbour, expert craftsman etc (Lemay 1999). Even the language of family: “mum”, “dad”, “brother”, “sister”, etc can be replaced by “service-oriented” words like “caregiver”, “carer” and even “junior carers” for siblings. The Victim role can even drive out existing valued social roles by depleting the energy needed for such roles as neighbour, friend, spouse and even parent (to other children)⁵. The Victim role can expand to affect every interaction with service providers and the service system in general even to the extent of notoriety in the service system. Others may shrink and quietly accept their fate as a Victim perhaps because of some perceived past sin. Some Victims might graduate into the Martyr role and receive (as in one example in Australia) a “Carer Long Service Award”. The point here is not to denigrate parents or to demonise services, but to acknowledge some systemic processes that are not always beneficial. It is also to acknowledge that current service paradigms can limit creative thinking. One can only change what one acknowledges.

The Role Dynamics for the Son or Daughter

The impact for the son or daughter is that for them too, the Burden role becomes reinforced. One sees this very prominently today with children being diagnosed with so-called “ADD” and “ADHD”. Descent into these negative roles of behaviour problem or learning disabled child requiring psychotropic drugs can be very quick and easy but can take years to escape from – if ever (Wolfensberger 1998). Indeed, the role of Burden is antagonistic to most valued roles; such as successful student, regular team member, or best friend, partly because the parents’ assumed Victim role is not sustained by valued roles the child *could* acquire. (This is another example of a negative role complementarity). For example, a parent can not make the claims of a Victim if the child is a successful student or team member. If the child is to acquire valued roles, the parent would have to be prepared to surrender (or avoid) the Victim role altogether. Some parents are very capable of doing this and even work actively against it; others though depend on that role for identity, reputation and services and may unconsciously and unwittingly undermine efforts to bring a better life to their son and daughter – and to

⁵ It is acknowledged that it is not only the victim role which can drive out other roles, but also the additional demands of being a “good” parent, as well as the normative (rejecting) reactions of family friends and community.

themselves. For example, it is not uncommon for many older parents to keep their disabled adult children *very* dependent on them for even the smallest things, and in a sense they become enslaved together (Wolfensberger, 2003).

Another difficulty created through the use of the respite model is that the nature of some disabilities may mean that respite actually exacerbates rather than resolves difficulties. For example, for some people, removal from familiar environments and familiar routines associated with overnight respite can actually increase anxiety or create a kind of sensory overload (Donnellan & Leary 1995). The result may be changes to behaviours during the respite experience or upon return to the family home. Longer forms of respite remove people from what is culturally typical thus further alienating socially devalued people, decreasing competencies, decreasing opportunities for freely-given relationships and enlarging a more devalued identity.

Asking Different Questions

As Nancy Rosenau asserts,

“This is not to suggest that respite is not useful: I am saying that service providers can miss the point when the answers elicited from families identify respite or placement as the need” (Rosenau 2002).

The requirement for artificial forms of respite via paid or organised arrangements comes largely as a result of the devaluation and consequent isolation a family experiences when their child is disabled, combined with the unwillingness and/or incapacity of others to provide freely-given support. As one parent said:

“If all my kids were normal, I would expect them to be in a creche if they were young, to spend a night or two with their grandparents, to be playing in the street or in a playgroup, or playing in the backyard or over with their friends. *None of these things are possible* when your child has a significant disability, so you get no break, no respite.” (Pearson & Moore 2001, p. 16, added emphasis).

A service (formal or informal) *is* required. The assumption has been that it should be “respite”. Nancy Rosenu encourages us to ask instead, “What would it take so that both the family and the child get a life?” Usually the valued ways of doing things provides a clue.

Respite is a means to something (getting a break, feeling refreshed), but in our current human service culture it tends to be stated as an end: “I need more respite”. Instead of seeing the need for a break as a disability specific problem, the alternative is to understand that *all* relationships are enhanced by time together as well as some time apart. In the course of everyday life this need is carefully balanced in a range of ways – rarely would this be referred to as “respite”. Family members or housemates spend time apart through their individual involvement in work, school, and leisure activities, by spending time in the company of friends or other family members, undertaking everyday

tasks, receiving formal or informal assistance from others, or going on holidays with friends.

Thus instead of “respite” being viewed as the ends or purpose of the service, and the means consisting of placements, allotted hours, respite houses or day services, the focus moves to what it takes to assist someone to live their life to the fullest. The means to do so are as varied as life itself. If a person has a range of activities they enjoy, in a range of valued environments, with a range of relationships with differing levels of intimacy, then they naturally will spend time both with and away from family. Real respite occurs as a by-product, a natural consequence of engaging in activities with others inside and outside the home.

SRV challenges us to think about how people might really acquire valued roles and avoid the descent into devalued roles that are often awaiting them. Certainly the use of means consistent with the valued culture (the CVA) will provide some clues, as well as those arrangements that serve the long term interests of a service recipient, their family and community. Circumstances are more likely to prevail and be sustainable if major parties (families and communities etc) obtain some reciprocal benefit as well. Valued roles commonly bring such reciprocal benefits. For example, instead of unemployed, one might become volunteer and later worker.

Some recent alternatives implemented by just one respite agency for young people up to age 20, as a deliberate effort to bring them into valued social roles, includes such initiatives as:

- workers supporting improvements to a child’s behaviour at home so that their role in the family and their relationship to the parent and other siblings improves;
- a worker accompanying a family on their annual holiday instead of leaving one member back in respite;
- implementation of a toilet training program at home for two children (thus avoiding the negative role of “incontinent” and the many restrictions it produces);
- a worker assisting an unconfident parent to venture out successfully with 3 children. Scouts and choir activities are now occurring after school as well;
- a worker teaching a child to travel by bus and to navigate road crossings;
- a worker teaching three children from one family to plan a menu, go shopping and take part in preparing a meal together;
- a worker and young person practicing their guitars together;
- a worker teaching soccer to the whole soccer team that includes the disabled team member he is providing “respite” to. Mum comes to watch; and
- a worker supporting students in an after school job in a supermarket.

Another important requirement for building valued social roles in a service in addition to *relevance*, is that of *potency*. You will notice in these examples how potency of delivery is achieved through the judicious and intense use of time, utilising valued and suitably challenging settings, social arrangements with other (usually valued) people, and the use of competency enhancing material supports and equipment and the right match between the child (in these cases) and the worker.

In another part of Australia respite is being thought of more flexibly by utilising informal and generic supports to also come into play, including:

- someone accompanying the family to a restaurant to assist the daughter to eat, enabling the rest of the family to simply enjoy her company and the restaurant experience;
- host family arrangements for *all* the children to holiday together;
- a neighbour regularly collecting the mail from the post office and purchasing bread and milk;
- an art tutor coming to the home to provide lessons;
- an aunt being present at busy times such as meal preparation and bath times.

SRV is not only applicable to formal paid human service arrangements, but will have much to offer for *informal, unpaid and natural circumstances* as well.

None of these activities involve bricks and mortar. Yet through these various activities, instead of the negative role of Burden, the person develops a variety of valued social roles – for example: sibling, family members, neighbour, friend, guest, club member, team-mate, colleague, participant, student, volunteer and so forth. The more valued roles a person has, the more likely they are to experience the “Good Things in Life” (Wolfensberger, W., Thomas, S., Caruso, G. 1996) and the more likely the family are to have a “Good Life” too.

Additionally, clarity around the identity of the primary service recipient would bring many benefits, for example, the service being extended to primarily serve the interests of the person with a disability. Thus the direct service serves the primary service recipient (the person with a disability), and the indirect benefits serve the secondary recipients (the family) instead of the other way around.

Notice how the above examples provide a clear and active role for service workers as well. Rather than passively filling time or pursuing activities that have little long term benefit, workers are acting with initiative and purposefully bringing competencies and improved images to the person. Such an active and responsible role is bound to have positive repercussions for securing and maintaining effective workers. *Everyone* needs to grow.

There may be some initial limitations, as with people who have extensive medical needs or whose situations are threatened by the presence with others perhaps because of infection risks and the like. But this does not negate the point that formal and informal support arrangements can be used to facilitate positive competencies and images for those people and to explore ways of crafting valued roles, and the ordinary experiences, involvements and relationships they bring into a person’s and therefore their family’s life. The more that these involvements increase, the more they will provide the break families require to pursue their own roles.

As Nancy Rosenau suggests, we need to ask different questions. These questions are not about what it takes to get respite but about what it might take to “get a life”.

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