SERVICES AND FAMILIES WORKING TOGETHER TO SUPPORT ADULTS WITH INTELLECTUAL DISABILITY

Proceedings of the
Sixth Annual Roundtable on Intellectual Disability Policy

Held on Thursday 29 November, 2011

Edited by
Christine Bigby and Chris Fyffe
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Services and Families Working Together to Support Adults with Intellectual Disability

Christine Bigby & Chris Fyffe

The annual roundtable on intellectual disability is convened by the Living with Disability Research group at La Trobe University in collaboration with other key stakeholders in the non government sector. It seeks to:

To provide a space for fearless debate, among interested groups, about policy within both the disability and the broader human service sectors for people with intellectual disabilities, with the intention of naming issues, clarifying concepts and ideas, exploring challenges, articulating solutions and informing practice.

Now six years ago, the principles of the Victorian Disability Service Act 2006 affirmed the importance of families in the lives of peoples with disabilities. In the last two years relationships between service providers and families of adult service users with intellectual disability have been raised in a number of different ways. For example:

- the Victorian Law Reform Commission focussed attention on the potential for supported decision making to assist the many situations which lie between the less formalised least restrictive approach and substitute decision making (VLRC, 2011);
- a national consultative process recommended that ‘working with families and carers’ be included as an additional standard in the revised National Standards for Disability Services (Meltzer et al., 2010);
- the Victorian Disability Services Commissioner highlighted in his annual report the complaints families make about the way they are regarded by service providers (DSC, 2011).

The foreshadowed National Disability Insurance scheme assumes the role of families, and proposals for tier 3 which targets people with severe impairment are predicated on the choice and control that will flow to people with disabilities and their families as a result of individualised packages of care and support. The Productivity Commission report however, tends to refer to people with disability and their families as if they are either one entity or interchangeable; giving little attention to who and how choice and control will be exercised by adults who have severe cognitive impairments (Productivity Commission, 2011).

Given the attention focussed on families in this range of forums, and the significance of families not only to the quality of life of people with intellectual disability but also in the relationships they have with service providers and other institutions, it seemed opportune for the theme of the 2011 Roundtable to be ‘Services and Families Working Together’. It is notable too that other parts of the health or disability sector, such as mental health services are recognising the importance of families in service users lives in standards and statements of practice principles (Commonwealth of Australia, 2010; Bouverie Centre u.d.)

The invited papers and discussions during the day fell into three broad themes: 1) the roles and importance of families in the lives of adults with intellectual disability; 2) the complex nature of relationships between families and service providers and the absence of policy and practice frameworks, and 3) whether and when family involvement in decision making that affects the life of a family member with intellectual disability should be more formally recognised, supported and monitored. One way of framing the discussion is through recognition that many people with intellectual disability are family members, and consider whether the role of disability services is to support families to be better able to support the quality of life of their family member with intellectual disability.

This paper summaries the main points arising for the 2011 Roundtable. Whilst it was clearly recognised that families provide the bulk of support for adults with intellectual disabilities who use a range of different services, much of the discussion centred around more intensive supports, such as shared supported accommodation, that are sometimes mistakenly perceived as totally replacing family care.

Dr Jane Tracy’s (2012) paper a Families Journey provided a powerful introduction to these issues by pointing to the centrality of family relationships in many people’s lives and crystallising unconditional love as the essence of such relationships. She wrote;

I love my son, Jack, and daughter, Annie, powerfully, fiercely, tenderly, unconditionally and forever. I need to say that, right up front, because I have felt that, at times, the core importance of
our family relationships in our lives has not been sufficiently recognized or valued. Jack and his sister are central to my life – and I am to theirs. To deny that is to deny a large part of who we are.

Despite the family Dr Tracy describes being both knowledgeable and resourceful, at times members struggled to fulfill their multiple other roles in addition to being the family member of a person with intellectual disability. Her paper details how deep and strong family relationships may not be acknowledged or harnessed by service providers, as well as the determination and relentless effort of some families to ensure their member with intellectual disability receives the best possible support and has an optimal quality of life. Dr Tracy’s paper anchored in the day to day life of one family, provided a foundation for the more abstract and theoretical issues in the other papers and discussions during the day. Her paper stimulated too recognition of the diversity of families, the variable and dynamic nature of members’ relationships with each other, and between families, staff and service systems. These dynamics and the diversity of families emerged as strong themes from the day – emphasising that making normative assumptions about families; and the goodness or indeed badness of these relationships can be both misguided and problematic.

Families: A Sense of Neglect

The high level policy intent and recognition given to families of people with intellectual disability in the 2006 Victoria Disability Act and more recently the Disability Standards has not been clearly conceptualised or translated into mid-level (i.e. ‘how to do it’) policies accompanied by resources to support implementation. Participants had a strong sense that the role of families of adults had been neglected, and at times even rejected by the service system. Some families do feel mistreated, misunderstood or excluded by services. Working with families it seems has become everyone’s and anyone’s task which may mean it gets little attention, and no one takes specific responsibility for championing or resourcing it. There are rarely professionals in adult services who fulfil functions similar to those played by social workers between the 1960s- 1980s, whose key tasks were liaison between services and families, support to families per se and of the relationship between people with intellectual disability and their families (Iacono, 2010; Bigby & Atkinson, 2010). There are now very few resources dedicated to this type of family work, nor was it clear where the knowledge and skills to undertake it are found in the current service system.

Families have been largely absent from policy processes and should, it was proposed, be recognised as much more than the relatively narrow conceptualisation of families as ‘carers’ that has been the focus of policy development. This issue is already subject of debate in the carers’ movement (see for example, paper on last year’s proceedings (Pierce et al., 2011)). Participants could not identify specific policies or practice guidance about services working with families, recognising such things were left to the discretion of each service. Discussions echoed the need for some action on this front which was identified in Tiffen and Kolmus’ (2012) paper. The recent round of consultations by the Office of the Disability Service Commission and a foreshadowed family engagement project suggests the Office is taking a leadership role to support better working relationships between families and service providers.

Diversity of Families

Reflecting the extensive literature on families of children with disabilities and the wider literature on family systems (see for example, Turnbull et al., 2011) families were recognised as being incredibly diverse, in terms of for example, size, membership, stage of the family life course, culture, cohesion, adaptability, socio-economic position and other resources. Changes occur over time in family service-relationships due to the dynamic nature of family relationships across the life course together with staff and organisational change which originate from staff turnover, changes in health or other aspect of family members’ lives, or their changed perceptions or satisfaction with the quality of support being delivered (Bigby et al., 2012).

Service system ideologies have framed the way families are perceived, and over time too resource short falls have created particular identities for families, such as for example older carers. The evolution of individualised service packages (ISPs) is creating new roles for families such as proxy manager of services, or employer of staff. There was a strong sense too that the parents of the adults now entering the adult service system belong to a younger cohort, with quite different and much higher expectations about rights and what is possible than their predecessors. Nevertheless there is little hard evidence for these assertions.
The point was strongly made that families are more than parents, and the extended and multi generation nature of families is rarely recognised. Discussion about the diversity of families led to questioning about those that may be perceived as ‘dysfunctional’ or ‘detrimental’ to the well being of the adult with intellectual disability. Families may for example hold different values from those espoused by disability policy, be seen as ‘holding back’ their relative, or undermining their confidence or self esteem (similar views may also be held by families about services). In turn questions arose about if and by whom such judgements can or should be made, and whether if such observations are mooted there is a role for family specialists within the service system to work with both staff and families in reaching common understandings about the place of family and services in a client’s life and negotiating relationships.

Distinct and Overlapping Roles – Families and Staff in Service Organisations

Families play a key role in influencing emotional development and early attachment which will impact on individual resilience and coping strategies in later life. They also shape an individual’s cultural, racial or class identity, or their values and world view. Family roles form part of a persons’ identity such as brother, sister, uncle or aunt that can create a sense of belonging and provide an opportunity to be someone other than a ‘service user’. Family functions extend far beyond their relationships with service systems and have been conceptualised in different ways. For example, in relation to children Turnbull et al., (2011) classify family functions as; affection, self esteem, daily care, spiritual, economic, socialisation recreation and educational. Dalley (1988) refers to ‘caring for’ and ‘caring about’. The latter involves direct hands on day to day caring tasks, while the former involves feelings of concern or anxiety and more indirect negotiation of care. Others have divided the support they provide into four components, emotional support, direct instrumental support, financial assistance and management of relationships with formal organisations (see for example, Seltzer, 1985).

There was a sense from the discussions that families bring important and perhaps unique qualities to personal relationships such as unconditional love, a long term view, lifetime commitment or emotional closeness, and deep connections to other community members that cannot be replicated by service providers. Some of the functions that families play are not exclusive and can overlap with those of staff in services. They do occupy however, a space outside the service system that has less constraints or conflicting demands than that occupied by front line or more senior organisational staff who for example have loyalties both to their service users and to the organisation that employs them. Litwak’s (1985) theory of task specificity supports this assertion arguing that primary groups such as family or friends and services each have particular characteristics that differentiate the type of support they are best able to provide. This means that family and service support are not simply interchangeable. For example, although the reliance of people with intellectual disability for everyday support may shift from their family to formal service systems, it is particularly difficult for formal organizations or those in paid relationships to have the long term or sole commitment to a service user similar to that of family members, or take an advocacy stance that involves monitoring quality of care and negotiating with services. Yet these tasks are critically important for people dependant on services to meet their day to day needs. The inability of formal services to substitute for some of the key roles fulfilled by families also emphasises the vulnerability of those adults with intellectual disability who lack strong family or other informal networks of support. This reinforces the point made in several papers about the importance of considering how to fulfil these unique functions for those without family for whatever reason. Whilst services cannot replicate aspects of informal support, such as long term commitment and affective support, they can support and foster development of informal relationships who can do this (Bigby, 2004; 2007).

In respect to relationships with services the group discussion threw up roles for families such as: gatekeeper to services or consent; advocate; negotiator of the service system; monitor of service quality; complainant; repository of knowledge about their relative with intellectual disability; interpreter of their life story, individuality or communication; provider of practical financial or day to day support and decision maker. The research reported in Bigby et al’s (2012) paper identified that involved siblings played four main roles in the lives of their older brother or sister who was resident in a group home: influencing formal care, supporting inclusion, making decisions or occupying formal role of next of kin and planning for the future.
Achieving greater clarity between the respective roles of staff and family was seen by some as important to avoid perceptions that services were taking over family roles or families were interfering in service roles by for example wanting to be involved in the day to day life of their relative with intellectual disability. The example was given of the work Homeswest, a small non-government organisation in Queensland had done in attempting to identify things that were ‘family business’ ‘service businesses’ and ‘shared business’ (see www.homeswest.org.au/). However, the rigid or prescriptive application of divisions such as this in practice may risk ignoring the diversity of families, and their dynamic, often negotiated role, in both people’s lives and in relation to the service system.

Relationships between Families, Services and Adults with Intellectual Disability

Greater complexity – what is the equivalent of family centred practice with adults.

The role of parents, and families of origin more generally in young adults’ lives, is relatively unexplored among the population of people without disability. Only a small body of knowledge has considered relationships for example that young adults living for longer periods at home have with their parents (Hartley, 1993). The situation between adults with intellectual disability and their families is likely to be more complex as they are less able to conform to the prevailing norms that characterise adulthood such as individuation – separation from parents and independence. Consequently relationships both within families where a member has intellectual disability and between such families and services are complicated by issues of autonomy and independence which must figure in negotiated partnerships.

A large body of empirical research and theoretical literature has developed to understand family systems, and underpins family centred practice with children and their families (Turnbull et al., 1986; 2011; Dunst et al., 1994). The premise of family centred practice is that the needs of a child and their family are most likely to coincide as the well-being of the child is largely dependent on that of their family. This may not apply to adults, and the family centred approach is seen to be superseded by a Person Centred or Individualised approach. There is no similar body of knowledge to that found in relation to children in family systems that has been applied to family relationships of adults with disabilities and their families of origin or about the development of partnerships between families and services. Pockets of knowledge do exist that provide important insights into these issues, for example, around planning for the future when parents die (Bigby, 2004; 2007); interdependence between middle aged adults and their older parents (Knox & Bigby, 2007; Walmsley, 1996) and a smaller bodies of knowledge about relationships between adult siblings with and without intellectual disability (Bigby, 1997; Bigby et al., 2012; McGraw & Walker, 2007; Heller & Arnold, 2010) and the continuing involvement of families after an adult moves out of the family home to supported accommodation (Seltzer et al., 2001). Work in the mental health field is beginning to develop principles for what has been termed family sensitive practice (Bouverie Centre u.d) based on principles of respect and inclusion. The Chief Psychiatrist’s guidelines for working with families and carers of a person with mental illness (2005) stress that evidence demonstrates that both consumers and carers have better outcomes and wellbeing when family members are involved.

What families want from services

A dominant theme was that families wanted to be listened to, treated with respect and their knowledge or expertise about their family member to be acknowledged and valued. They do not want to be made to feel redundant. They also want their family member to be safe and to have trust that the service is delivering consistent high quality support, and that staff are clear about what the support they are providing. The points raised during the discussion were very similar to Turnbull et al.’s (2011) seven principles of family and professional partnership; communication, professional competence, respect, trust, commitment, equality and advocacy.

A framework or guidelines for family – adult service user – service relationships

A strong theme that emerged was that too little guidance is available to both services and families about both how to support and what to expect from family- adult service user -service relationships. Each family and organisation has been left to develop their own approach, which can mean little consistency across and in some cases within services. While it was recognised
that the diversity of families would render meaningless a prescriptive approach to family staff relationships, the need was identified for a framework that would ensure relationships were addressed and guide their negotiation. A Conversational Tool-Kit was suggested to act as a guide to the issues necessary to be considered in how family – adult service user – services can work together, and lead to a negotiated agreements between them. It would cover issues such as: what each expected to know about the other and the person with intellectual disability, when and how, i.e. mutual expectations of communication, care provided and behaviour; responsibilities for sharing information, planning and implementing plans, decision making, responding to adverse events crisis, expected processes for resolving disagreements (Tiffen & Kolmas, 2012).

An agreement on topics such as this would provide an individualised guide to the service family partnership around each adult with intellectual disability, to inform actions of all staff be they permanent or casual. Although the framework for discussion would be similar the outcome and guide for each family would likely be quite different. It would be a living document that changed as individuals or family member circumstances changed. Services would need to find ways to build the mutual expectations in the individually negotiated guide into the way staff interact with each service user's families, and deal with continual flux of front line staff.

Much appears to be known about difficult staff family relationships but much less about those that work well. The La Trobe research group talked about work in progress that is examining ‘good group homes’ which is suggesting that in these homes, staff- family relationships are characterised by; respect, a confidence to challenge either parties actions, receptive to dialogue, values of front line staff that are aligned with those of the organisation, a balance between permanent, casual and newer staff, so there is always a core known faces among staff.

**Multiple ways of supporting families to better support their adult service user member**

The gradual decline of mutual support networks for families that flourished around day centres was recognised. However, the value of mutual support groups to families and as a means of education and information dissemination was reinforced by a recent project undertaken as part of the LIRDs initiative by the Eastern region service network (Frawley & Bigby, 2012). The role of the Carers Association in supporting families using similar mechanisms was also acknowledged. Other strategies suggested included greater involvement of families in discussion about policy and strategic directions of services, or in the management or governance of services. Another relatively unexplored avenue in Australia is the role of circles in both affirming the varied roles of families and in recruiting others outside the service system to supplement family resources.

**Decision Making**

The right of people with intellectual disability to exercise control over their own lives, participate, and be supported in decisions that affect them is recognised in the Victorian Disability Act, 2006. Any form of restriction on these rights, due to capacity or perceived risk, through use of substitute decision making is based on the application of the principle of the least restrictive alternative (Guardianship and Administration Act 1986, Disability Act 2006). But just as is the case with families, recognised rights have not been well conceptualised or translated into mid level policies to guide practice of front line disability services or to support families. Notably there are well developed professional practices around substitute decision making found in the Guardian/Advocacy program managed by the Office of Public Advocate.

Factors in the broader context of welfare systems and the international rights movement have identified flaws in current policies and proposed new approaches to support for people with disabilities to exercise their rights to decision making. The stronger recognition of rights contained in the UN Convention on the Rights of Persons with Disabilities (‘UNCRPD’, 2006) challenges the use of substitute decision making, and the binary option of either appointment of substitute decision-makers or no appointment of any kind offered by current guardianship regimes. Issues identified with these options and leaving primarily decision making in the informal (and often family sphere) are:

- the absence of support for informal decision makers;
- the failure to recognise their legitimacy by some business, government or community institutions;
- the absence of scrutiny or monitoring to ensure decisions reflect best interests and take into account the preferences of the person with intellectual disability.
- no avenues other than formal guardianship to resolve conflict between family and service providers about notions of ‘best interests’

For example, whilst both family and support staff can be effective enablers of decision-making, their support can also be paternalistic or reflect the preferences of others rather than the person with a disability; and may indeed be contrary to the values and rights embedded in current policy (Bray et al. 2000). Qualitative research has revealed this occurs with care workers in Britain, making decisions based on their own view of a good life, rather than standing in the shoes of the person they support (Dunn et al. 2010).

Jo Watson’s paper (2012) illustrated the depth of knowledge required for someone to have any confidence in representing the preferences of a person with severe or profound intellectual disability, and her paper suggested a model to guide informal decision makers. Discussion during the day referred to parallel work being carried out in the Department of Human Services into supporting decision making. A DHS guide which is now publicly available sets out principles that should inform supported people with a disability to make decisions (DHS, 2012). This guide does not really address the issues raised in discussion about the range of decisions and different contexts in which they arise, and the current uncertainty of families, disability staff and others professionals about who has the right to make decisions on behalf of a person with intellectual disability or to support them to do so.

Examples were given where different expectations existed between the health and disability systems about decision making powers and support. This must also be seen in the context that people with disability will have more opportunities to make decisions as service reforms such as self-directed or individualised funding schemes become more widespread. Decisions about services are likely to become more individualised and delivery move further into the informal sphere of people’s homes away from external scrutiny. This raised issues about the need to be alert to potential for abuse and safeguards to protect people with intellectual disability from exploitation. The increased focus on management of risk by organisations will also impact on decisions individuals may be expected to make. Tensions for staff working with individuals between avoiding risk and taking risks that may expand experiences may mean organisations manage risk by abdicating decision making responsibility, and handing this role to families or clients.

These trends have stimulated legal and policy debate about the concept of ‘supported decision-making’ and potential benefits of a more formal approach to endorsing informal decision makers and provision of support for decision making. John Chesterman’s (2012) paper highlighted some of these issues and set out the some of the proposals for change to guardianship legislation currently under consideration (see also Chesterman, forthcoming), which include support decision making or co decision making agreements, a new volunteer scheme program managed by the Office of the Public Advocate to support such initiatives, and recognition of long term family decision makers as formal advocates for their family member with intellectual disability. Whilst the potential value, particularly of supported decision making arrangements was recognised, questions were asked about the evidence of their operation and success elsewhere, and the resources necessary, both in terms of money and people to successfully implement this type of scheme. The issue touched on in earlier discussion about the disadvantageous position of people with intellectual disability without strong family or other informal support was raised, and highlighted the need to develop programs to support recruitment of community members to be part of micro boards or circles of support.

Terry Carney’s (2012) paper provoked discussion about the untested nature of some of the new types of supported decision making schemes and challenged the sense of certainty that benefits would flow from formalisation. For example, the radical new legal models developed in Canada to empower people with disabilities to make their own decisions through ‘assistants’, ‘micro boards’ or ‘co-decision making processes’ (Gordon 2000; Birmingham 2009), have been little used in practice and have been criticised for failing to deliver effective support (Browning 2010; Joffe 2010). It has been speculated that this divergence between apparently good ‘law on the books’ and ineffective ‘practice on the ground’ has been due to ‘over-reach or ‘net widening’ (Lutfiyya et al. 2007). An understanding of the common and divergent issues for people with different types of impairment, at different stages of the life
course, or in respect of different types of decisions is necessary to help to avoid the unnecessary application of laws or supported decision-making programs to those who do not need assistance. In turn this understanding would enable programs can be targeted more effectively to avoid a likely dilution of the intensity of orders if applied across too large and diverse groups (Lutfiyya et al. 2007).

Conclusions

History reveals that disability service systems have primarily focussed on adults with intellectual disability with families viewed as less relevant. Although more recent legislation and proposed service standards have more clearly recognised the significance of families and the importance of their relationship with services, the Roundtable highlighted the extent to which the role of families in the lives of adults with intellectual disabilities continues to be either misunderstood or underestimated by the service system. There has been no concerted emphasis on families participating in policy development in relevant, frequent or timely ways, and little attention has been paid by service providers to incorporating the role of families – beyond perhaps that of ‘carer.’ Ironically, when adults with intellectual disabilities do not have family or friend supporters, the service system acknowledges this lack and has gone to some effort to (re)-establish those relationships.

As providers become increasingly person-centred in their approach, this inevitably means becoming more involved with family members. However, as the Roundtable discussion revealed the mechanisms to strengthen, clarify or negotiate relationships between adults with intellectual disabilities, family members and services do not reliably exist. What’s more, formal and legal mechanisms can only be minimally relied upon to supplement the more frequent and far reaching informal processes.

All the papers point out ways that adults with intellectual disabilities with good family relationships are better placed to achieve quality of life. The long term goals for families and for services inevitably coincide. That is, how can each adult with intellectual disability be optimally supported and live well, including when parents are no longer alive. The challenge for service providers is therefore to define what role and capability services need to support families to enable improved outcomes for adults with intellectual disabilities, while at the same time supporting the individual. This role may extend to support to families in their own right.

Three potential but largely unexplored areas of importance were identified in the Roundtable’s papers and discussion, 1) the role of services in supporting and strengthening family relationships of adults with intellectual disability, 2) supporting families so they are better able to support the quality of life of the adult with intellectual disability, and 3) acknowledging the inevitable aging of parents earlier rather than later, ensuring that services and families form the type of partnership that optimises what each contributes to the quality of life of the adult with intellectual disability. All three it was agreed require knowledge about family systems, and self reflective, mediation, negotiation and relationship building skills. Proposals for the disability services system to give greater attention to relationships with families whilst also acknowledging their diversity, through initiatives such as a Conversational Tool Kit (Tiffen and Kolmas, 2012) are worthy of further consideration. Finding ways to guide an individualised negotiated working agreement between each service user, their family and service provider may go some way to putting flesh on the bones of the new legislative and policy recognition of the importance of self-direction and autonomy of adults with intellectual disability but also the significance of families in their lives. For many people with intellectual disability their relationships with family members will help to optimise both their quality of life and involvement in major and minor decisions about their own lives.

References


Chief Psychiatrist (2005) *Working together with families and carers*, Melbourne, Victoria: Mental Health Branch, Metropolitan Health and Aged Care Services Division Victorian Department of Human Services


Disability Services Commissioner (2011). Our year in review: Melbourne: ODSC


Meltzer, A., Muir, K., & Dinning, B. (2010). Report on the consultation data for the revision of the National Standards for Disability Services: Development of a consultation package and analysis methodology to support a revision of the National Standards for Disability Services Canberra Department of Human Services, Disability Services Division.


Productivity Commission. (2011). Disability Support and Care: Report no. 54 Canberra: Productivity Commission


Watson, J. (2012) Supported decision making for people with severe to profound intellectual disability, ‘We’re all in this together, aren’t we’ In C. Bigby & C. Fryffe, Services and families working together to support adults with intellectual disability. Proceedings of the Sixth Roundtable on Intellectual Disability Policy. Bundoora: La Trobe University.
A Family’s Journey

Jane Tracy, Centre for Developmental Disability Health Victoria

There’s nothing extraordinary about our story. It is, in fact, its very ordinariness that makes it important. Details vary but the stories of countless other families echo the general themes of our own journey.

I love my son, Jack, and daughter, Annie, powerfully, fiercely, tenderly, unconditionally and forever. I need to say that, right up front, because I have felt that, at times, the core importance of our family relationships in our lives has not been sufficiently recognized or valued. Jack and his sister are central to my life – and I am to theirs. To deny that is to deny a large part of who we are.

In the beginning…

The journey Jack and I have shared started 26 years ago. It began with my first experience of the miracle of pregnancy and birth; the astonishing, breathtaking tsunami of a mother’s love; and the overwhelming desire to enfold, nurture and protect my child. Those feelings only intensified when my son was identified as having disabilities.

Around the time of the diagnosis we felt the uncertainty, fear, shock, confusion, guilt, inadequacy and deep, deep sorrow experienced by so many parents; a seemingly endless swirling black fog of grief that isolated and threatened to smother us.

We were helped to move through the gloom and into life’s sunshine by the guiding love, support and practical help of our family, friends and professionals … and the passage of time. But that fog still lurs in the background of our lives and I know it will do so forever. Sometimes its presence goes unnoticed, sometimes its wisps briefly darken the day, and sometimes its tendrils clutch at our heart threatening to engulf us again. Time has enabled us to learn to recognize its shadow as it approaches, to keep our eyes on the light while it passes, to know who to reach out to when its darkness menaces, to recognise the way through the shadows into the light and, most importantly, to believe that there will be sunshine ahead.

Those early years were very hard at times, but there was also much joy and laughter. We shared snuggles, kisses, hugs, and the songs and parties that fill the lives of so many parents with young children. We met new friends and shared our adventures. We delighted in Annie’s arrival and the wonder and excitement of her growth and development. We basked and played in the sparkling sunshine, laughter and radiating warmth she brought to our lives. Together we shared the fun, the playfulness, the music, the achievements and the pride of childhood.

Growing up…

Through Jack’s preschool years we learnt to focus on all he could do, his many abilities and gifts, and we came to better understand why he found some things so very difficult. We were shown ways the community could support us: the service system, aids and equipment, respite and financial assistance. And we found out about the attitudes of others; experiencing both the supportive, embracing warmth of inclusion and belonging, and the cold, lonely, harshness of exclusion.

In those days playgrounds were not accessible for children who needed a wheelchair to get around. I spent many hours carrying Jack as I clumsily clambered around play equipment to provide him with the physical experiences – and fun – of climbing, tunnels, slides, seesaws and swings. I often felt stared at, judged and pitied by other parents who could sit neatly by as their children played independently. The separation and distance I felt from the experiences of parents in the ‘mainstream’ made the friendships I formed with other parents sharing a similar journey to my own all the more precious. I formed lifelong friendships with those on similar paths to my own at that time. We felt we belonged together as outsiders, and were accepted, supported and understood by each other in ways we greatly valued.

The preschool years were a difficult time but we were fortunate in receiving the care we needed. We were wonderfully supported by the love of our extended family, comforted by the understanding and friendship of other parents, and guided by the thoughtful knowledge, assistance and wisdom of professionals. Although certainly challenging at times, there was also great joy, happiness, warmth and fun in those years. When it came time for Jack to go to school I feared the best years of his life were over.

But I was wrong. The school years were a time of expanding horizons, greatly increased community engagement and a sense of belonging to and being valued by our community. It was the time in which we developed a sense of our rights and
our abilities, as a family and as individuals, to participate and contribute.

Jack and Annie went to the same mainstream schools, at both primary and secondary level. This was a validating, including and strengthening experience for every member of our family. We learnt, through being part of these school communities, that some people saw Jack’s disabilities long before they could see him as a child, while others immediately recognized him as a little boy who wanted the same fun, friendship and new adventures at school as the other children. We chose to spend our time with the latter group.

The primary school we selected for Jack celebrated difference. The culture embraced – and delighted in – the ways in which every child is unique. Each child has a different family background, ethnicity, mathematical ability, sporting ability, musical ability – and physical, cognitive, communicative and social ability. It was a place where everyone was extraordinary, difference was expected, and everyone was valued. When asked how many children with special needs attended the school the principal replied “Three hundred and fifty. Every child has special needs, some we get extra funding to support, some we don’t, but each child is special and each brings something unique and valuable to our school community”. This was not empty rhetoric; it was the reality experienced by children in the classrooms and playgrounds every day.

The school was a place where families were embraced and supported, and rarely judged. At one point in our lives Jack was having many seizures in the early morning. These were associated with marked irritability and he often became angry with and aggressive towards Annie before school. We frequently arrived at the classroom door late and in a disheveled state: Jack still fitting, Annie with scratches and bruises, and me on the verge of tears. The school staff never judged us, but rather provided us with the understanding, support and the practical help we needed to get through that very difficult phase in our lives.

Local families who knew us as part of the school community would greet us happily when we met in the supermarket aisle, understanding Jack’s loud vocalizations and lurching movements as expressions of his delight at seeing them. It helped us to feel accepted, embraced by and warmly included in the community. In contrast, families who did not know us often responded to our noisy presence by suddenly developing an intense and urgent interest in products elsewhere in the store, leaving us feeling self-conscious, awkward and excluded.

Our school embraced and supported us, and we greatly appreciated and enjoyed our place in the community; we developed a new confidence through the sense of belonging we experienced. We loved being part of our school with all the learning, excitement, experiences, friendship and fun that came with it. Jack was proud of being part of his school and, when he saw children in the school’s uniform in the street, he would proudly point to himself and say “me” meaning “that child and I belong to the same community”. When the time came for Jack to move from primary to secondary school, I feared that the best years of Jack’s life were over.

But once again I was wrong. Secondary school brought new friendships and growing independence. There were a wider variety of subject choices, and together we built a curriculum for Jack that he enjoyed and enabled him to explore new subjects, like woodworking and cooking, while backing away from subjects that were just not his areas of skill or interest – like mathematics and Chinese.

Mathematics is just not Jack’s ‘thing’. For over 10 years teachers and family struggled to develop his numeracy. We tried multisensory learning techniques; individual tuition and group work; experienced teachers and peer learning; using his interests as motivators; and we tried movement, music and songs. By the time he went to school he had 1:1 correspondence to 3, and has never moved beyond that. At a certain point we decided to accept that it was just not a strength. He continued to have exposure to numerical concepts of course, particularly through educational computer programs that he could explore while classmates worked on concepts at their level of ability, but when he went to secondary school we took the pressure off achievements in that domain.

Chinese was a source of conflict. The school wanted Jack to experience as much of the curriculum as possible. I acknowledged the sound principle behind this advice, but believed that common sense was also required. Jack’s communication includes many vocalizations that are his way of approximating particular words; and they can be quite a challenge to interpret. The meaning of “oo” or “beh” or “lah” may be clear from the context IF one knows what is important to him at the time AND the assumption can be made that he is speaking English! Adding a language mix to the range of possibilities makes the task completely
impossible. It was clear to me that it was much more important for Jack's confidence, quality of life, relationships and future that he experienced optimal success in his communication attempts. I insisted. Learning Chinese was definitely an optional extra that could safely be foregone.

Secondary school also brought with it the chance to go on school camps. Year coordinators emphasized the importance of the camps for developing a sense of community among the students, and as opportunities for students to explore their abilities. Parents were strongly advised to support their children to participate in these exciting and challenging new experiences. But when I enthusiastically agreed, they expressed their surprise at my expectation. They did not see participating in these camps as a realistic possibility for Jack. Staff acknowledged the potential benefit, but found it hard to see past the many potential difficulties and obstacles that seemed to obscure the path forward. We insisted, and with 'encouragement' (advocacy), and the support of Dept. of Education policies and mediation, we prevailed. A trouble-shooting planning group of people who knew Jack well was formed, hurdles were identified and negotiated one at a time, and the path was cleared in time for him to go to camp. Each time it was a resounding success with both teachers and other students coming to a new appreciation of Jack's many abilities, courage, sense of humour and fun through sharing the rigors of camp together.

When the time came to leave school, once again I was sure the best years of his life were over. And once again, I was wrong.

**Becoming a man…**

Jack has been happy from the first day he started the programs at his day support service and he quickly made new and lasting friendships.

Within six months he and his girlfriend, Sarah, had found each other and since then that relationship has been at the core of Jack's life. They have been a couple for nearly eight years now and are uniquely special to each other. Although Jack is generally very protective of his own personal space, he loves kissing and cuddling with Sarah and even enjoys her blowing raspberries on his face or tugging at his nose. For them these are expressions of their physical intimacy. Through Jack, Sarah has become an important part of our family and often shares family events and occasions with us. She and Jack are at the top of each other's guest lists for birthday celebrations and Christmas parties.

We have supported them on many 'dates' together as they enjoyed movies, concerts, meals out and spending time at each other's houses.

Jack is a very visual person with an extraordinary visual memory. For days, weeks and even months after Sarah has visited the house, Jack points out to us the places where she sat or walked, the rooms she went into and the movies they watched. Recalling these details to discuss with Jack as he seeks to share them severely taxes the memories of family and staff, but for Jack they remain vivid and are very important to share. They are happy memories that fill the house, and provide him with months of ongoing pleasure.

Jack has also developed strong male friendships, characterized by physical jostling and larking around. Tony, the friend he first identified when he started at the service nearly eight years ago, is still his closest friend (apart from Sarah). These two important key relationships Jack has shared with Sarah and Tony are not based on words. They have taught me a great deal about the 'chemistry' of friendship, and the many ways people connect and share without speech.

The staff at the day service have consistently held a holistic view of Jack's life. They have included the family in planning meetings, embraced our contributions, and respected our need for varying degrees of involvement, relating to other life demands, at different times. I have always felt they are genuinely interested in Jack's life before he arrived at the service, and that they value the family's knowledge, experience and understanding that comes from sharing our lives for so many years. When all is going well, the staff support Jack to share his joy, news, achievements and excitement with us; when trouble arises they include us in problem solving in respectful and sensitive ways. Despite many staff changes over the years, the quality, flow and continuity of the service for Jack has rarely been adversely affected. Jack's friends share his experiences during his day programs and when a staff member leaves and another arrives there remains more that is the same for him in the environment than is different. His friendships therefore support his ability to cope with systemic and staff changes – they underpin his resilience.

Jacks enjoyment of his friendships, activities and achievements at his day service is at the core of his life. He does not want or need a 'break' from an environment that brings him so much pleasure. Holidays therefore are of little attraction in their own right, and must include special and
enjoyable activities if they are not to be rather a
disappointment and a pale shadow of his rich and
full life at his work.

The struggle for independence…

When Jack was in his early 20s I became
increasingly irritating to him. He wanted to be an
independent young man, but continued to need a
great deal of help with organization, support and
personal care tasks. He was frequently intensely
angry with me when I asked him to do something,
like get up, go to bed, or get in or out of the bath,
or the car. He resented me washing him or cutting
his nails, and fought me when I tried to help him
in the toilet or to get dressed. But he could not do
these things on his own.

As a family we devised strategies to avoid
situations in which I would have to direct him
what to do. We found remote devices to turn the
TV, DVD player and music on and off so I was
not seen to be responsible; if he thought I was
behind these limitations of activities he enjoyed
he would attack me with hateful fury. Family
members stepped in for me and helped whenever
they could. They would, for instance, help me by
picking Jack up to go to family events as he would
often refuse to get into the car with me. I would
have to travel separately. We got professional
advice and various behaviour strategies were
tried. Few alleviated our difficulties.

We tried respite services, both in-home and activity
based. Our experiences of in-home were not good;
we found carers unreliable, and those we had
seemed to have little initiative, common sense...
or interest in Jack! On one occasion I came home
to find Jack in front of television without food or
drink, and the worker sitting at our kitchen table
surrounded by my books on stepfamilies. On
seeing me, he started talking about his personal
step family situation. I wasn't interested!

Interchange activities were great. They provided
Jack with experiences he didn't have with me and
new friends, and me with some weekend time to
spend with other important people in my life. For
a time Interchange was wonderful for us both. But
then, as Jack increasingly wanted to express his
independence from me, I frequently could not get
him into the car to get there or, once there, out of
the car to participate.

Essentially nothing I did really addressed the
underlying issue; Jack didn't want his mum
fussing over him any more – he wanted to do
things on his own. He was a 23-year-old man with
a fierce desire for independence – and limited
opportunities for experiencing it. I understood but
I couldn't change the reality for him.

Despite being acutely conscious of the reasons he
was behaving this way, I was deeply wounded and
saddened by the brutality of the way he expressed
his desire for independence. It is profoundly
painful when someone you love looks at you with
intense, hate-filled anger and tries to hurt you, to
drive you away. The hurt is felt both physically
and deep in one's heart.

It was my increasing difficulties in managing
these behaviours, both physically and emotionally,
that lead to my decision to put Jack on the Register
for accommodation. Even though logically I
understood it was what he needed, I still felt, on a
primal level, a soul-destroying sense of failure in
my ability to care for him.

After 2 years he was offered a place. I experienced
the phone call and the process of decision making
as heart-wrenchingly confronting and highly
stressful. I didn't know what to do, and wanted
to avoid the almost unbearable choice I had to
make. There was a chasm between my rational
understanding of what needed to happen, and
my emotional response. Was I providing my son
with the opportunity for an independent life or
was I rejecting him, abandoning him to the care
of strangers? Was I courageously assisting Jack to
become a man and forge an independent life, or
was I betraying the trust he put in me to nurture
and protect him? I was wracked by agonizing
internal conflict, and overwhelming, paralyzing
uncertainty.

The place he was offered was in a house with four
people all decades older than Jack. They were quite
passive and socially isolated. Each had an area of
the house where they would sit or wander, with
minimal engagement with the others. I feared Jack
would not form relationships there and would be
lonely and isolated. On the other hand, it was,
on the whole, a quiet house, and I felt he would
probably be safe there. The environment was
physically attractive, with a spacious, light and
bright feel and a wide corridor well suited to Jack's
energetic way of getting around. From his first
visit Jack enjoyed sprinting down this passageway
in his wildly ricocheting unstable gait. The house
was in a leafy green neighbourhood, not too far
from my home or from his day program. I had
specified in the application for the Register that
continuing in his day program with his friends
– including Sarah – was an essential prerequisite
to my accepting any accommodation offered to
him. It was unthinkable that Jack would lose the relationships with his girlfriend and other friends that were the core of his life, whatever difficulties we were having at home. The houses in the street had no front fences; there was a nearby park and the promise of a local café. The area had the potential for developing a sense of community. Was this a home in which Jack could be happy? I didn't know.

Jack cannot speak; his communication is based on a vast and ingenious repertoire of signs, vocalizations, facial expressions, body language and the use of visual cues. Those who don't know Jack often first assume he cannot communicate, but he has a great deal to say and expresses himself very creatively, resourcefully and effectively if you take the time to learn and understand his communication strategies. His success in communication therefore depends heavily on the skill, knowledge and interest of those with whom he wants to share.

Although physically he is a young man, he remains profoundly vulnerable to neglect and abuse, in the way a young child is vulnerable. He cannot report what he is feeling in ways that are unambiguous and clear. He cannot report what people have said to him, or what he has experienced or how he is feeling. I was frightened for him. To pass the responsibility for caring for him over to strangers was contrary of every maternal instinct I had, but I knew I had to try.

A home of his own...

When Jack moved to the new house we all struggled with the word 'home'. His new house was, in theory, his new 'home' – but it didn't feel like one. He had moved out of 'home' (with me), and yet we all talked of Jack coming 'home' for the weekend. It was very confusing for me, and for the rest of the family, and no doubt was for Jack too. We still struggle with this at times, but have generally settled on 'Jack's home', 'home with mum', 'home with dad', 'home with Abba' (Jack's grandmother) as acceptable representations of the current reality.

After he moved into his new house Jack's anger and assaultive behaviours directed towards me settled almost immediately. When he came home for weekends he was happy and relaxed and allowed me to help him as required. He seemed now to have the independence he craved during the week and was happy to enjoy familiar family routines at home each weekend. That part of the move was wonderful for me – we could be happy and relaxed together, and enjoy each other's company once again. But not everything went well.

Jacks first stormy year... challenges at home

The first year at the house was terrible for Jack, for me and for all those who love us. In that first year there were 3 house supervisors (and 3 team managers) with many months between with no house supervisor, and no effective leadership at the house level for various reasons. There was a heavy reliance on casual staff. Jack had no Person Centred Plan or Key Worker for over 6 months. There were many, many changes of staff – some good changes from my point of view, but some not so good – and many, many breakdowns in communication between the house, family and day service. Rapid and repeated staff changes at the house meant staff often did not know Jack and I could not trust that Jack was being well cared for. On one occasion I rang to ask how he was. The staff member I spoke to called to the other on duty “It's Jack's mother on the phone. She wants to know how Jack is... Which one's Jack?”

Staff did not have/make the time to get to know Jack and his communication strategies. This meant there was no one at the house with whom he could talk and be understood; he was therefore isolated and lonely. I struggled to have my knowledge of Jack recognised as being of value to staff. This even extended to medical issues. I felt frustrated, frightened and powerless when the potentially serious implications of his epilepsy were not acknowledged, and staff did not appreciate the importance of ensuring everyone knew how to effectively treat his seizures. I felt he was both physically and emotionally unsafe and that my concerns were not being taken seriously. I made a video of his seizures, put it on the staff computer and requested all new and casual staff be required to watch it before working at the house. I don't think this happened consistently. I made signs about how to recognize and treat Jack's seizures that I then insisted staff put up in the staff room and bathroom (to remind them not to leave him alone in the bath). I felt I was doing all I could, but staff were not taking their share of responsibility.

Jack has complex medical needs, and one component of him moving to supported accommodation was passing over to, or at least sharing with, staff the responsibility for addressing these needs. This was challenging. On one occasion I was told that if I wanted the staff member to accompany Jack to
a doctor's appointment with me I would have to pick them both up, Jack from his day program and the staff member from the house, and afterwards drive Jack back to his day program and the staff member back to the house as s/he didn't drive. I did so, because I wanted to involve house staff in order to build their capacity to share the responsibility for Jack's complex medical care with me.

It is not possible to care for and support Jack without getting to know him. This seems self-evident to me, but I felt my comments to that effect were regarded as reflecting an unreasonable expectation. When I tried to share my knowledge and understanding of Jack and what I felt was important for him, I often felt dismissed. My written summaries were filed but suggestions and recommendations were often not acted upon. Some staff seemed to have the view that a 'new' life had started when he moved into the house and that the 'old' life he had shared with us was somehow now irrelevant. Some found our family's expectation of close and ongoing involvement with Jack was rather a nuisance and a distraction from their work.

One of the most important contributors to Jack's quality of life is having something to look forward to. It can be a movie or musical stage-show he wants to see, a date with his girlfriend, an outing with a friend, going on holiday, a party, Christmas, Easter, birthdays – or any number of other activities. It must however be something of interest and meaning for Jack, something he has played a part in choosing and it must be planned ahead of time. Jack must have a way of initiating conversation about this important upcoming event, of sharing his anticipation and excitement with others (e.g. photos and text in a photo-sheet as a visual communication aid). I felt a sense of frustration and failure that I was not able to convey the central importance of this to Jack's quality of life to the house staff.

I talked repeatedly about Jack's essential and fundamental need for visual communication tools to enable him to initiate conversations and share and chat about things that were important to him. He needed visual timetables and pictures of the staff and photos of him and the other residents – so he could better understand staff rosters, house routines and the people with whom he was now living. He needed ways that he could initiate conversations about events and people, both past and future, that were important to him. I made many communication tools myself – but did not feel supported by the house staff. Despite providing the house with the technology required (laptop computer, colour printer and ink, laminator and pouches), no visual communication aids were made by staff for Jack in the first 12 months he was there.

Jack is very adept at using a computer mouse. We had felt it was important to support him from a young age to develop skills in using the computer to provide him with options for independent entertainment. When he moved into the house we bought him a computer on which he could play games, look at photos and YouTube clips, and listen to music. He could turn the computer on and off himself, and navigate to where he wanted to go but, if the system wasn't working, problem solving was difficult for him. I explained this to staff, and asked that they check every day that the computer was plugged in, the mouse and speakers were connected and so on. To my frustration I repeatedly found, on visiting the house, that he was unable to use his computer as the electrical plug had fallen out/been removed for vacuuming and not been replaced, the mouse or speakers had fallen down the back of the table or cords had become tangled or disconnected. This was immensely disempowering for Jack as it took away an important source of independent activity and pleasure.

In that year Jack's behaviour became increasingly problematic at the house. At first he was reluctant to join in house activities, including meals. I thought this was entirely understandable as he didn't know or feel comfortable with the other residents and staff, didn't understand the house routines and expectations of him in that environment, and the food was different to that we ate at home. He was also more active and expected and demanded much more interaction than the other residents; staff appeared to find it difficult to appreciate the needs of this active, social and 'talkative' young man.

I was again and again told that house staff were too busy (doing the laundry, cleaning, paperwork, shopping, errands, or CERS … or incident reports!) to spend time with Jack learning about the things that were important for him. I wanted the staff to 'hang out' with him and do things together to get to know him. I asked them to make photo sheets with Jack about things that were important for him. I wanted the staff to do things with all the residents so Jack – and the others – could build a shared set of memories and an associated
I fought for him every step of the way, and it was told he should be restrained in the bus. I refused. I was told he should be on sedating medication for his behaviours. I refused. I was told he should be left at the house for 3 months before I took visits home were unsettling him and he should wouldn't eat with the other residents at the table. I was told he should be put on a liquid meal replacement because he sometimes hostility. I was told that his weekly visits home were unsettling him and he should be left at the house for 3 months before I took him home again. I refused. I was told he should be put on a liquid meal replacement because he wouldn't eat with the other residents at the table. I refused. I was told he should be restrained in the bus. I refused. I fought for him every step of the way, and it was highly distressing and profoundly exhausting. Staff thought my demands were unreasonable and excessive, and I felt their level of care was inadequate and unsafe. We had little trust in or respect for each other.

**Jack's first stormy year... challenges at work**

Then the situation got much worse. The building in which many of Jack's day programs were based was to receive much needed renovations. This necessitated all people and activities moving to a temporary venue for 10 weeks or so. Planning for the move got underway and at first all was well. But during the last weeks at the old premises Jack's behaviour started to change. He became increasingly reluctant to get on the bus at the end of the day to go back to his house. Instead, he would run away from staff and rampage up and down the street in a highly distressed state. When staff tried to talk with him, reassure him, reason with him and encourage him to get on the bus, he would lash out at and assault anyone who came close to him. He injured several people during these episodes. He also ran on the road, putting himself at significant risk, and hit and damaged cars in the vicinity. He had never done this before, and it was very distressing for everyone to witness this highly disturbed behaviour. For some weeks it took up to 2 hours to get Jack on the bus to go home at the end of the day.

I think there were three main reasons for these behaviours. The first was that the changes at his day program, on top of all he was experiencing at his new home, exceeded Jack's capacity to cope and adjust. The second was that I think he feared losing those aspects of his day that were so important to him. His friends, his girlfriend, the activities he enjoyed, the staff he liked, were all part of his day activities. They were the core of his life and I think he felt he might lose them all when they all moved out of the familiar venue. He understood what was known and familiar was ending, and I don't think he grasped the move would be followed by a new beginning with the people he knew and cared about.

The third reason related to the issues at his new house. Jack is an energetic, social young man who needs to feel he is cared about, as well as cared for. He needs the security of familiar people and routines in order to feel valued, understood, safe and happy. He needs opportunities to 'burn' his youthful energy in healthy active pursuits. Unfortunately for much of his time at the house...
none of those needs were addressed. Reasons for this included rapid staff turnover, limited staff hours available and, perhaps, because the other residents tended to be less demanding, low expectations of engagement between staff and residents. In contrast, at his day program Jack was surrounded by people he liked and who liked him. People were interested in him and he was actively engaged and his communications were listened to and understood. There was an atmosphere of warmth, energy, excitement, and connection and Jack was known and valued. At his home, there was little interaction with the other residents, often staff did not know Jack at all (casuals, agency), and there were few opportunities to share and chat with anyone. I think it was a cold, boring and lonely place for him. No wonder he didn’t want to get on that bus.

Jack expressed his unhappiness in aggressive, assaultive, destructive and noncompliant behaviours – drawing further negative judgment from house staff. His behaviours each afternoon when leaving the day program became increasingly problematic – resulting in day program staff taking over from the house staff in transporting him home each afternoon for many months. He required 1:1, and for a time 2:1, staffing for this journey.

Day program staff, in consultation with house staff, drew up an Action Plan and a Behaviour Support Plan. Unfortunately many actions required from house staff did not occur. I wrote my thoughts about why Jack was behaving as he was and shared my ideas for how his needs at home could be better met, but they were not acted upon.

It was a terrible year for Jack, our family, and for me personally. I felt desperately sad, and tremendously guilty that Jack was suffering in this way. I nearly gave up many times, wanting to pull him out of the house and bring him home to live with us again. My mother, who has always played an enormously important part in Jack’s life, was likewise highly distressed, and desperately wanted to have Jack back at home where she could care for, protect and nurture him. She understood the reasons for Jack moving out of home, but for her, the cost was just too high.

It was only my daughter’s firm loving support and wise guidance that stopped me from acting on my maternal desire to bring Jack home. She gently helped me see that if we withdrew Jack from his accommodation we would be back where we had started – and reminded me of how difficult that time had been for us all. She told me what a relief it had been to her when Jack went into supported accommodation because she had always wondered how she would cope if I was no longer able to care for him. She couldn't see how she could live her own life while being responsible for Jack's day-to-day care. Now, she said, with him receiving that care through accommodation services, she could clearly see that she would be able to continue to play the roles of sister and advocate, whether I was there or not; this greatly relieved her anxiety and concern. We all needed Jack to have a place of his own. Annie came to meetings at the house with me, helped me write emails of complaint, and spent hours talking through what was happening and what we should do about it; many times we cried together. We started to prepare our case for a formal complaint through the Office of the Disability Services Commissioner.

My own ability to work was severely undermined at this time. I found it increasingly difficult to concentrate on work, to organize and remember what I needed to do, and to maintain my attention on important tasks. My focus narrowed to the survival of my family and I simply no longer had the intellectual or emotional energy to do my job. I came within a breath of resigning from the workforce as I was so distressed by my inability to function at a level I considered to be acceptable. I felt my life force, my focus and my energy were being totally consumed in my struggle to address the issues surrounding Jack. I simply had no more to give.

I became increasingly anxious and irritable at home. I was highly distressed by the environment in which Jack was living and his reaction to it. We brought him home every weekend, and showered him with love and shared numerous activities with him to try to build his resilience so he could better cope with his life during the week at the house. I made numerous communication aids for him to give him the best chance of being successful in his communications while at the house. I felt the pressure on me was immense and utterly exhausting.

I was very fortunate to have the endless love and support of my family, particularly my daughter, mother, brother and husband. I was also enormously appreciative of the ongoing support and help provided by those working within Jack’s day support service. I trusted, and felt great relief and comfort in the knowledge, that they cared deeply about the difficulties we were experiencing and pain we were in and were there for us. They were generous with their time, patiently listening
as I struggled to articulate and understand what was happening and what I could do to make life better for Jack. They provided gentle guidance, shared their knowledge and experience, and supported Jack and I in whatever ways they could.

Rainbows and sunshine...

And then, after Jack had been at the house about 16 months, our lives turned a corner and gradually life started to improve. A senior manager was appointed within the accommodation service who respected and valued my role in Jack’s life and my knowledge of and experiences with him. She took the time to listen to us, was interested in our story and came to better understand both Jack and his family. She validated my concerns, affirmed the importance of the family in Jack’s life and appreciated my efforts in fighting for him. Her communication was open, warm, respectful, honest and professional. She strongly believed in the principles of Person Centred Active Support, and Positive Behaviour Support – and had the experience, knowledge and clarity of vision to see how these should and could be implemented at the house to help improve Jack’s life (and therefore his behaviour). Between us we developed common goals, and built a sense of partnership, respect and trust.

At first I was difficult to work with. I was hostile, defensive and despairing that anything would change. She listened gently, acknowledged the pain we were in and did not try and defend what had happened. I felt she genuinely cared about us and was ‘on our side’ and, after the many months of conflict, hostility and distrust we had experienced, this was an enormous and welcome relief. She advocated for us, provided strong leadership for the staff and facilitated the appointment of a House Supervisor who was likely to stay for at least 6 months. Stability of leadership at the level of house supervisor was associated with the staff gradually becoming a more cohesive and stable team and the functioning of the house started to improve.

Consistent staff at the house meant the residential and day program staff could begin to get to know each other, and so to communicate and work together more effectively. Slowly, very slowly, trust between everyone working with Jack was rebuilt. Jack’s PCP was dusted off and the actions to achieve the outcomes decided upon months before were begun. Jack’s key worker took a more active role and he and Jack started doing some great things together, including providing the support Jack needed to take Sarah out on dates and invite her to his house for dinner. Staff began to know, like and appreciate Jack and to understand his behaviours, communications and abilities – and he became happier and more relaxed. The house staff and family slowly began to trust each other, to listen to each other’s perspectives, to problem solve and plan together and communication between us vastly improved. My behaviours – and Jack’s – gradually settled and we both became much easier and more pleasant to work with.

Since then there have been other challenges and difficulties for us all, including 3 more house supervisors and 3 more team managers; there are now no staff members working at the house that were doing so at the time Jack moved in two and a half years ago. But over the last 18 months a more stable staff team has enabled relationships and communication to improve. Discussions and planning meetings are now held within the context of a group of people who all genuinely care about Jack and are keen to work together to support him to have a fulfilling, rich and happy life. Sarah has been to the house for meals, and recently Jack was supported to proudly take her to a Ball. He still comes ‘home’ to his family each weekend, but trust is slowly being built and planning is underway for him to stay at the house once a month so he can share leisure activities with his housemates. The House Supervisor recently organized a Christmas party at the house to which the family was invited, and this was a great success and a very happy day for all involved. Jack helped set up the party, and was immensely proud to be hosting such a big event at his house.

We are now a better team, and therefore more able to support him. Family, residential service and day support service are working together to ensure he feels safe, secure and valued and has opportunities to grow, learn and enjoy his life.

The foundation pillars of life...

I regard Jack’s family, home and day support service as the three current pillars of Jack’s life. He needs us all, and we complement each other in providing him with care, experiences and opportunities.

Since Jack started at his day program, the people there have central in his life. He is challenged and nurtured, stimulated and stretched, and warmly embraced and supported. His friends, including his girlfriend, are there. It is a community he proudly feels is his own, a group to which he
belongs, a place he is known, liked, included and valued.

His home is his own space; a place where he is surrounded by familiar people, objects and routines; a place of intimate knowledge of his housemates and in-jokes; a place with opportunities to grow and develop in independence and control. He has developed good relationships with his housemates, and has a particularly tender and touching relationship with one of the more vulnerable residents. He thoroughly enjoys going out with them to the pub for dinner, or to a movie or disco. He is now a man living in his own house, with a corresponding sense of security, identity, place and pride.

As Jack’s family we have, of course, played a vital part in his life and will continue to do so. We have been his carers, advocates, playmates, healthcare providers and therapists, financial providers, patrons, bankers, limit setters and opportunity providers, and his decision makers when required. We have made the agonisingly difficult judgments around surgery, putting him through days or weeks of pain and discomfort for potential long-term benefit. We have struggled through those times together: laughing as we tried to use new equipment, and crying when difficulties were encountered and recovery seemed endless. We have nurtured him, played with him, taught him, planned and anticipated, partied and celebrated with him. We have delighted, fought, and laughed and cried with him. We have shared picnics and movies, stage shows and musicals, concerts and festivals, parties and holidays with him. We have moved house, travelled and explored together. We have rejoiced with him in his love for his girlfriend and supported that precious relationship in every way we could. Most of all we have loved him.

**The way ahead…**

**So what do we want for Jack in the future?**

We want him to be happy, healthy and safe. We want him to love and be loved. We want him to nurture important friendships and have opportunities to make new friends and share fun and fresh experiences with them. We want him to have a strong sense of being valued by and belonging to his family, his friendship group and his community. We want him to spend his days in activities that are meaningful and enjoyable for him. We want him to feel encouraged, stimulated and challenged. We want him to have opportunities to try new things, attempt new challenges and to feel the pride and satisfaction of achievement. We want him to feel he is continuing to learn and grow. We want him to feel proud of his contributions to the lives of others. We want him to have something to anticipate with pleasure and excitement. We want the same things we want for all our children.

**How do we see the family’s ongoing role in Jack’s adult life?**

Jack is our son, brother, stepbrother, grandson, nephew and cousin. We want to be respected and appreciated for our knowledge and understanding of Jack, and for our deep and lasting love for him. We want our lifelong place in Jack’s life to be valued and supported. We want the life journey we have shared with Jack so far to be treasured as a part of his precious life experience, a part of who he is, and something those who care about him are interested in and help him to remember, share and cherish.

We want to be partners with service providers in caring for Jack, and to be involved in planning and problem solving. Sharing Jack’s life journey has given us a rich source of information and experience from which to draw insights and ideas for the future. Our current priorities for him are to achieve and maintain optimal physical and mental health; to have as much control and choice in his life as possible; to have an effective communication system to optimize his success in as many communication exchanges as possible; to have opportunities to maintain and develop his social life, treasuring old friendships and creating new relationships; and to choose how and with whom he spends his leisure time. These are things we all want for ourselves – and we want them reflected in his ‘Person Centred Plan’.

As his family, we want to be recognised as one of the key pillars supporting Jack’s life. A pillar that must be acknowledged, protected and reinforced as time goes on and relationships change and evolve. We want to continue to include Jack in family events, and to share activities with him on a regular and frequent basis. As he now lives in supported accommodation we can pull back from the day to day organization and provision of his care, but we can only do so if we can trust that he is cared for and about by others. We understand and respect his need for independence, but also recognise his desire to part of and belong to our close family group. Our lifelong relationships with him are irreplaceable, our connection with him unbreakable, and our deep love for him incomparable and invaluable. Jack will always be part of us, and we will always be a part of him.
Important principles for service providers working with Jack and our family.

We want service providers to:

- Respect and value our knowledge and understanding of, and the love we have for, Jack.
- Appreciate and support our lifelong commitment to, relationships with and love for Jack.
- Acknowledge our journey. Understand that we have had many experiences along the way that influence the way we see and understand those we have today.
- Work in honest, open partnership with us. We know nothing is perfect. Involve us in problem solving – we have a great deal of experience. Trust and good communication is the key.
- Develop and maintain a consistent staff group so relationships, communication and trust can be built with us. Remember trust takes time to develop, and can be quickly destroyed.
- Identify the foundation ‘pillars’ of Jack’s life and consider them when planning. For Jack these ‘pillars’ are family, friends, day activities and home.
- Remember that whatever our differences, we want our son/brother to be cared for and about, to have fun and friendships, and to have the happiest, healthiest, richest and most satisfying life he can have.

The keys to building the trust required for successful working relationships lie in both family members and staff listening to and valuing each other’s views and perspective; in demonstrating respect for each party’s contribution to Jack’s life; and in maintaining the focus on the goal we share: that of enhancing Jack’s opportunities and the quality and enjoyment of his life.
Relationships in Later Life Between Group Home Residents with Intellectual Disability, their Siblings and Staff

Christine Bigby, Department of Social Work and Social Policy, La Trobe University, Ruth Webber, Australian Catholic University, Barbara Bowers, University of Wisconsin – Madison.

The centrality of families in the lives of adults with disabilities is acknowledged, in the significant disability policy reforms that have been foreshadowed in the past two years. A national consultative process recommended that ‘working with families and carers’ be included as an additional standard in the revised National Standards for Disability Services (Meltzer, Muir & Dinning, 2010) and the Productivity Commission report that recommended a National Disability Insurance Scheme referred to choice for people with disabilities and their families as if they are synonymous (Productivity Commission, 2011).

At the same time the need to recognise more explicitly the roles families play for adults with cognitive impairment and vice versa, families often precarious standing in relationships with formal service or business systems and the shortcomings of a ‘hands off’ least restrictive approach to involvement in decision making has gained some prominence. For example, reflecting imperatives derived from the United Nations Convention on the Rights of Persons with Disabilities (UN 2006) the Victorian Law Reform Commission has made similar suggestions to those in other jurisdictions about the need for a more graduated and regulated approach to support decision making of people with cognitive impairment. It is argued this is needed to replace current guardianship regimes where formal mechanisms are narrowly restricted to removal of rights and appointment of substitute decision makers (VLRC, 2011; Office of Public Advocate (South Australia), 2010). The importance of families in the lives of adults is highlighted by the high proportion of complaints to the Victorian Disability Services Commissioner (2011) that originate from families. Embedded in many of these complaints are issues of the way families have been treated by services, which raises concern about the nature of service family working relationships.

Despite visionary policy over the past several decades the under resourced disability service system continues to rely heavily on families to ‘care’ for their adult children with disability often into middle age and beyond. The parallel carers’ policy and service sector initiated by government was designed to cushion these demands. Its focus however has been on caring dyads and support for primary caring roles. This has tended to gloss over the fact that people with disabilities are part of complex family systems which play multiple, diverse and changing functions in the lives of all family members. That this system continues to be important beyond the cessation of direct hands on ‘caring for’ (Dalley, 1988) by family members and includes more indirect ‘caring about’ roles has largely gone unrecognised in both disability and carers policy (a notable exception is Pierce, Fyffe, Ilsley & Paul, 2011).

Juxtaposing Person Centred and Family Focussed Approaches for Adults

Since the 1990s, striving to be person centred has become a core feature of contemporary health and social service systems (Carr, 2010). Embedded in this notion are key concepts that Mansell (2005) suggests should underpin services for people with intellectual disability: individualization, services are finely tailored to the needs of wishes of the individual; responsiveness, services adapt to the changing needs and continually shape support to the needs of the individual and; control, individuals exercise control over the type of services and support they receive. The focus in this individualised and person centred world is on the dyad of individual and service provider (rhetorically at least) and both the research and practice literature is strangely silent about the triad of service provider, family, and adult with intellectual disability.

A notable exception has been in respect of middle aged people with intellectual disability living at home with older parents (Krauss et al., 1996; Knox & Bigby, 2007; Bowey & McGlaughlin, 2007). This literature has recognised the wider family system and the importance of joint work with service systems. For example, Krauss and her colleagues found that the majority of adults with intellectual disability living at home with older parents had siblings with whom they had close relationships and were an avenue for emotional support and companionship (Krauss et al.1996). The place of adults with intellectual disability in family systems was also illustrated in an Australian
to families in the post parental care phase of life, when an adult with intellectual disability may be living in shared supported accommodation rather than the family home. Yet as people with intellectual disability age, there is a much increased likelihood they will live in some form of supported accommodation (Bigby, 2010). While a small body of research has considered the resident – family – service triad in the aged care field, almost no research has been undertaken in respect of adults with intellectual disability in out of family home settings.

Family – Service – Person Triads in Supported Accommodation Services

Victorian research suggests that although approximately half of middle aged and older group homes residents are 'known well by no one', 75% are in touch with a family member at least once a year and 33% at least monthly (Bigby, 2008). This study also found most residents support plans did not have any specific goals or strategies relating to contact with family, and where strategies did exist in most cases they had not been implemented. The absence of social workers or other professionals in disability services mandated to play a 'go between' role, similar to that found in institutions between staff and families, and in a service system where very few residents have an on-going relationship with a case manager, questions are raised about who or what role in disability service systems have responsibility to facilitate resident – family relationships or support family – service engagement, and what is the nature of these relationships (Bigby & Atkinson, 2010). The data reported here are part of a larger study that investigated how group homes support residents to age in place and the circumstances in which a move to residential aged care occurred. One aspect of this study, already published, found that decisions for such a move were made in haste and seen as a fait accompli by involved family members. Although family members took seriously a role of overseeing the well-being of their older relative with intellectual disability, they had little knowledge about their rights or avenues to safeguard untimely or inappropriate decisions being made by professionals (Bigby, Bowers & Webber, 2011). As this was a study of older group home residents, the majority of involved family members were siblings rather than parents. The present paper uses a sub set of data from the study to consider the questions; 1) What is the relationship between older group homes residents with intellectual disability and their involved
sibling without intellectual disability; 2) What roles do siblings of older group home residents play in their lives and 3) What is the relationship between siblings of group home residents and staff in group homes and how do they work together.

**Method**

A grounded theory approach was used to collect data from group home and other organisational staff, and siblings about relationships between siblings, residents and group homes staff. Due to the limited communication capacity and in some instances complex health condition of residents they were not interviewed about their perspective of these relationships. Eighteen clusters, that each comprised a resident, an involved family member, house supervisor and accommodation manager were recruited from 4 non-government organizations that managed group homes in Victoria. A subset of 13 clusters where a sibling was the involved family member is reported here. Residents were aged between 52-81 years. Face to face interviews were conducted in the initial data collection round, followed by phone interviews at six monthly intervals or sooner if an unexpected event occurred that led to a residential move. This meant the number of interviews differed between participants, but all were interviewed between 2 – 5 times during the course of the 3 year study. Sixty two interviews were conducted with siblings, 50 with house managers, and 8 with the service accommodation managers. Data were analysed from the perspective of staff and family members using a constant comparative method, line by line open coding followed by identification of categories. As the analysis progressed categories were refined into overarching concepts and a beginning model of relationships. The study was approved by the relevant University ethics committees and all names have been changed.

The origin of quotes is shown by participant number, followed by F to indicate family, HM to indicate house manager, and AM to indicate more senior organisational manager, the final digit indicates which interview it was drawn from. Thus 10 F 3 is from the third interview with family participant 10.

Older group home residents were recruited to the study on the basis they had an involved family member, which means relationships with less involved siblings were not investigated.

**Findings**

**Sibling relationships – ‘million and one positives’**

All siblings had a close and valued relationship with their sibling with an intellectual disability (resident). Siblings did not regard their resident brother or sister as a burden but rather drew attention to what they had gained from the relationship. This is illustrated by the quote from a sibling in the sub heading above and another sibling who said of her brother, ‘he’s contributed a different direction to our lives’. A sense of empathy characterised the siblings’ relationships, illustrated by frequent comments about what siblings thought life was like for their resident brother or sister and what their state of mind might be. For example, one sibling commented about the recent holiday she had organised for her brother, “he probably loves the time away” and another commented that she “really didn’t think her brother was unhappy”. Siblings conveyed a strong sense of wanting their brother or sister to have the best life possible, both emotionally and materially. Reflecting their life long relationship siblings knew a great deal about both the current and past life of their resident brother or sister. Siblings who controlled their brother or sisters’ finances were keen to spend money, particularly inheritances from parents, on ensuring a good life in the here and now rather than amassing savings. Talking about the management of her brother’s money one sibling said, “the money is there to make it happier for him” and another, “it’s very important for us that Steve has what he needs”. Siblings had frequent contact, at least twice a month, either in person or by phone with their resident brother or sister as well as with group home staff. The intensity of their involvement varied as illustrated by these comments:

I wouldn’t say an active role but they take an interest (5HM3)

regular but not intensive. (5F2)

omnipresent. (2F3)

The intensity and nature of sibling involvement in the life of their resident brother or sister had changed over time, influenced by both their own aging and that of their other family members. In particular enabling their brother or sister to visit their home or taking them out to various activities appeared to diminish with age associated problems. For example, siblings said:
I don’t do as much with him now because if he gets knocked or like anything or has a fall. (4F1)
I don’t have him at home with me anymore because my husband’s eighty this year and he has a macular degeneration. (10F2)

Siblings Roles – Safeguarding Wellbeing

Siblings were involved in a wide range of activities directly with their resident brother or sister, and indirectly with group home staff or others such as health professionals. All of these activities aimed to foster or safeguard the emotional, social and physical wellbeing of their resident brother or sister. They illustrate four major roles played by siblings: influencing formal care; complementing formal care and promoting social inclusion; occupying formal roles and decision making; and securing their future. The first three involve often intensive interaction, sharing information and negotiation with the staff of the group home, about things such as timing of visits, appointments, medical treatment, family events, and change to routine or lifestyle. These four roles are briefly illustrated in the following sections.

Influencing formal care – ‘otherwise it’s just leaving it up to them [staff]’

Siblings used various strategies to influence the nature of care and support. Most commonly they monitored what happened in the group home and ensured they were informed about particular aspects of their brother or sister’s care. Explaining their role siblings said for example, “I’ve always got my ears and eyes open, to see if things are okay” (8f1 2) and “I want to pre-empt anything that might go wrong” (2F1). Sibling expectations differed about the frequency of communication and type of information that should be conveyed by house staff. For example, one sibling said, “when she’s off [day program] of course I’m told’ (5F2), while in contrast a staff member said a sibling expected to be told about, “a major one [event] yes but not the day to day stuff” (1HM1). Another sibling described her informal mode communication with staff.

we appear to have fallen into a very nice pattern of having a meal about once every month, six weeks, with two of the four carers that are there with Samantha and sometimes a couple of the other clients and so… that provides an opportunity to have an informal chat about what’s going on. (5F2)

Siblings appeared to have reached implicit agreements with staff about what they were and were not told, and when they would be consulted about a decision. They said for example.

One thing the staff asked me was about doing the normal prostate cancer checks and I said no. (6F2)
They did initiate finding the specialist, talking to people and that sort of thing, so they did show the initiative there, but then they brought the information to me and we discussed it and agreed on who would be the best person, and that we would go together and talk to the person. (13F3)

As the quote above also illustrates some siblings chose to share some tasks, particularly medical appointments with staff which enabled them to provide additional advocacy or support for their brother or sister. When siblings identified a problem with care they were willing to challenge staff, and as illustrated in a later section sometimes stepped in and took over from staff. For example, one said, following protracted concerns about her brother’s medical condition;

I am going to email him [house supervisor] and say that I particularly want this doctor. I actually feel I have a say here and you can do what I say… you actually have to and I’ve never done that before. (15F2)

Complementing formal care and promoting social inclusion – ‘doing what we can to include him’

Siblings were an important link to other family members, relationships and social activities beyond the group home. They complemented the support group home staff could provide, were important in fostering family based identities for residents and supporting their wider social inclusion, as these examples illustrate:

…when he’s here at Christmas, everybody comes and sees him. My son has been up several times but mainly it’s my brother and myself. (10F2)

…then last Saturday for example, my sister, her husband, daughter and two grandchildren were all over from Tasmania and we’d arranged to have afternoon tea picnic in the Flagstaff Gardens. Well because most people in our family only see Steph about every year, they certainly don’t cope with just how much effort it takes to get her from point a to point b so I picked her up from the house. (2F2)
Steve is very excited about going to his nephews wedding next month and he was very excited, they had their engagement party in the city so he came with us for it. (9F3)

I took him to a barbeque, with some friends and he was fine. But he was a bit over the top what mother would say making a spectacle of himself but who cares? He was having a great time and nobody minded in the least, he likes to the centre of attention. (15F1)

The strong feelings that siblings had for their resident brother or sister were evident in the actions they took to ensure their emotional wellbeing, by for example paying for counselling, ensuring they were the person who told them bad news, accompanying them to medical appointments or going out for a treat afterwards.

So I’ll go with him and I think it will make it a bit better because urology examinations aren’t particularly nice especially on the initial one, so it will be better if I’m there with him. (1F2)

I always take her for something, sort of a treat and definitely a cuppa ..and give her a chance to bring up anything that might be worrying her. (2F1).

Formal roles and decision making – ‘they are one of the players’

Siblings occupied various formal roles, such as health guardian and administrator, but most commonly their status was simply that of next of kin. Both staff and siblings perceived decision making on behalf of the resident sibling to be a ‘very grey area’.

It’s still dubious whose Robin’s guardian…if anything it’s probably VCAT that has got the responsibility for him, but it’s a very, very grey area, like I’m only his administrator. (3F3)

Both our parents died over 15 years ago… he’s been in our care since, I have an administration order for him but I don’t have a guardianship order. (6F1)

Uncertainty about decision making responsibility was exacerbated by a common assumption by doctors which was endorsed by staff that, as next of kin, siblings had the right to make medical decisions. Yet in regard to service related decisions their role was less clear and they were ‘just one of the players’. For example,

For instance I recently had two different doctors ask me if the polyp they removed was cancerous would I just want it left there and let her die. (13F3)

If Saul needed an operation as staff we don’t sign for anything usually next of kin would sign which would be his brother but he’s still not his legal guardian. (1HM1)

Well it’s a four way task, you’ve got the GP, Saul and you’ve got Chester and you’ve got me. (1F3)

Securing their future – ‘I promised mum and now they [my own children] have to promise me’

The fourth role that siblings played, which didn’t involve staff was ensuring their own succession, that someone else, usually one of their children would have the same enduring commitment to their sibling. Some had already begun to share some of the more instrumental aspects of their role such as money management with younger family members.

My mother was getting old… I inherited William… my brother and I are his guardians .. my son looks after his money. (10F1)

I took it under my wing...my husband Paul has always been really good and I’ve got two boys who I know would take over and do whatever. (4F2)

Fluctuating and Unscripted Staff Family Relationships

The degree of confidence or anxiety about the care provided to their resident brother or sister fluctuated, as staff or organisational changes brought new ways of working, and different personalities or competence levels of staff. As one sibling said, “you just watch the new people and see how they are” (1F2) and another said, “we have had a few funny people over the years actually” (5F1). As confidence fluctuated, siblings adjusted their monitoring activities, vigilance or interference in care, which at times led to increased friction with staff.

These quotes illustrate this type of adjustment;

There’s been glitches on all things... there’s been things that you sort out or question... I would have been far more vocal probably about three to four years ago because I was not happy about how the situation was then. (1F1)

There is a new house supervisor which takes some adjustment… the accommodation is the same, I don’t think the supervisor is very satisfactory … it hasn’t perhaps been as satisfactory for me as it has been in the past. (9F3)

It is a bit of a worry to me that there is such a high turnover of managers… I think they’ve all
been really good and they are not all the same, they’ve had different ideas … just a little bit of a worry that once you get a good one, then they’re off somewhere and you have to hope the next one is as good. (13F2)

The need to adjust involvement was exacerbated by the absence of organisational scripts or protocols that set out expectations about communication and relationships between staff and families. As one siblings said, “staff are unclear what they are meant to communicate with families” (8F2). This meant each new staff member could set their own ground rules for communication, and siblings highlighted the changes that occurred in the information they received from staff over time.

The last year’s been paradise because there was so much friction with the former supervisor and so much dissatisfaction and she couldn’t get medication and I was left out of the loop frequently and so for the last twelve months it’s been wonderful. (2F3)

An easy partnership

Most commonly staff and family members had an easy working partnership characterised by mutual respect, good communication, joint problem solving and shared tasks. For example house supervisors and agency managers commented on the working relationship between direct support or organisation staff and families saying, “they work with the workers and the workers sort of work with them” (3HM1) and “we are working in a spirit of cooperation with the sister” (12, 13AM). Similarly siblings talked about being in a team with staff, “I feel that we are a good team” (13F2), and “I think we’ve always worked well with the people in charge and [name of day program] and house supervisors” (9F1). Another said of the

relationship with staff, “very comfortable, the communication’s good… the staff and I are involved, from the word go”. (2F3)

The description below of how a sibling and the house staff worked together captures the nature of their easy relationship that enabled tasks to be shared without difficulty. It also illustrates how each acknowledged and respected the others role, by staff recognising the anxiety that prompted immediate action by the sibling, and the siblings recognition that staff required this information about the medical appointment for their on-going role in her sisters care.

…the other day when I was with Steph and she had this inflamed eye, I just took her straight to the GP and then went home and Grace [house supervisor] was there and I said you know just observe and we’ll see if it’s okay in twenty four hours but he doesn’t think it’s conjunctivitis,… do you want me to fill out a form and she said no forget it. Very comfortable, the communication’s good…the staff and I are involved, from the word go,…Oh, they’re wonderful, the staff, they really are, and straight away the permanent staff member who was on Friday afternoon he immediately started the two-hourly chart and we encouraged Steph maybe to have a sleep-in on Sunday… So she is going to confer with the GP who knows Steph very well, and see which was the best way to go, and then I’ll go out on Wednesday morning and with the staff, we’ll have a look at the eye and jointly decide what we think, and then ring the eye specialist. (2F3)

A sense of mutual respect was evident from staff and siblings for their respective contributions to the quality of life of the resident with intellectual disability. For example siblings commented about staff:

I regard them very highly… I don’t know what they think of me, but I regard them very highly anyway. (13F1)

The two women in charge they were just incredible, and once they found out exactly what was wrong with Steve they encouraged him to walk up to the corner, which is, well for Steve, it was a fair hike. (9F4)

In turn staff recognised and admired the role that siblings played in their brother or sisters life, commenting for example:

I think Ned’s really lucky because he’s got wonderful sisters. (1HM1)

…she’s really the ideal sister, she’s intelligent and persistent and has a genuine love for Christine, there’s nothing in it for her… except her love for her sister. (13HM3)

This mutual respect meant that relationships were sufficiently robust to withstand direct talking or questioning about particular issues. For example one sister said:

I always felt and my sister did too, that we could step in with these two other women [staff] because we knew they were after the very best for Steve, so there was no kind of friction about speaking out, as long as, I mean we are never unpleasant about it, but you felt you were both moving in the same direction. (9F3)
An uneasy partnership – an intermittent phase

At times easy partnerships became uneasy, sparked by a change in staff or in their regard for the role of the sibling. Uneasy relationships were characterised by a breakdown in communication or a loss of confidence by a sibling. For example, remarking on her current relationships with the group home staff one sibling said, “I can’t trust them, it’s as simple as that”, another commented

I can’t pinpoint one thing but the first time I met her last year… I was absolutely floored because one of the residents came round the corner and said he wanted to speak to her and she screamed at him to go back, couldn’t he see she was talking. I’ve never been aware of any of the house supervisors behaving like that and particularly when you’re speaking to a close relative of someone you have in the home… It certainly was and both my sister and I don’t feel comfortable with the house supervisor. (9F5)

Other sibling comments illustrated the changed and poor communication that occurred at times.

I thought that’s fantastic, that’s terrific and they have apparently a new team leader who I’ve never spoken to, who hasn’t contacted me and who is never on the phone when I ring up. (8F2)

I’ve told them I would like to know every time he goes to the doctors or something, but they don’t… I had problems with a range of things that were happening in the house, decisions being made about what her brother liked to do and to go out when she felt he would rather stay at home, issues with over eating in and staff attitudes to food… but found it really difficult to take on and deal with. (15F)

An uneasy relationship could also mean that a sibling stepped in and took over an aspect of the care of their resident brother or sister which was normally the responsibility of staff. All the examples where this occurred related to dissatisfaction with the way staff managed health related issues and particularly their capacity to act as health advocates for the resident with health professionals as these comments illustrate.

I was convinced that the issue was nothing to do with dementia at all and that it was related to this new drug. Anyway, though, nobody would accept that and it took months and months and months and months, you know, of observing him and so on and finally luck swung our way and the local GP gave him an increased dose of this new drug much more than he should have done in one go and so the symptoms were just so obvious, so I immediately got onto the neurologist. (8F2)

There was this total muddle happening. I sent a begging email to JT who thank goodness made an appointment… I said I’d take him for the next weekend, I thought it would be better if he came home. Instead of having police or psychiatrists. (15F)

So I just pulled her out that day got her sponge bag and a few things in an overnight bag and after the doctor’s appointment just turned up at the door of A and said “we’ve got an emergency”. (2F1)

Negotiated Relationships

Both staff and siblings actively managed their relationships with each other; to safeguard what they thought would be the best outcome for the residents’ wellbeing. Siblings strategically avoided conflict to ensure optimal communication occurred as these examples illustrate.

I’ve started doing that… ringing, rather than just walking in. Particularly if there’s an issue. Sort of announce my arrival and its working better. (8F2)

There are different ways of dealing with this, in a group home so I’ve decided I’m going to do strictly one on one… I’m a bit torn, you know without wanting to come down on everybody like a tonne of bricks, but on the other hand wanting to protect Ollie, and not just Ollie. (15F)

I always tend to go to the top, I get feedback from the people immediately but I also then go back and go to the top and just say right what is your consideration, what is your explanation of this situation that’s just occurred. (1F2)

One sibling had become involved in the advisory and governance structures of the organisation to try and bring change at the organisational level rather than simply tackle the individual issues he identified were happening in the group home where his sibling lived. At times siblings avoided conflict by letting some issues that they were unhappy with go or acknowledging the difficulty of staffs' job. For example,

I’m holding back, it was just such a business I went through when we had the previous team leader, a couple of years of absolute stress about it all so I’m holding back at this stage and just watching, they’re feeling their way, things are changing. (8F2)
The organisation has looked after him for over thirty years, nearly forty years, I can’t, I wouldn’t criticise them, they take him to the neurologist and they look after him extremely well, but he does drink a lot of tea, or they’re always making cups of tea, and I know with my husband who is older, well he’s got a bit of a prostate problem, but you know, when he stops drinking tea after four o’clock he doesn’t have so much problem at night. (10F2)

It is a big change and there are things that we have brought up... we are the first to admit it’s a big job and it takes time to get to know the people living in the two homes... unless the same person goes each time, it’s sometimes difficult for myself and my sister to chase up things because no one knows what is happening and I wouldn’t think it was anyone’s fault but with casual staff, people who don’t even know the person very well which, I’d much rather it was staff that you knew they were going to be able to fill in if someone else was away but I suppose it’s like everything, you can’t have the perfect situation, you do the best you can. (9F4)

Staff valued the contributions that siblings and others in their family made to the lives of residents but also appreciated that it made their job easier. For example talking about the involvement of siblings’ staff said,

he’s [brother] just great, they stay out of the way and let us get on with it but you only have to ring and say do you want to take your brother for a week and they say yes. (3HM1)

it makes it a lot easier to get things done. (2,9HM1)

brothers very good he will come and help sort out tantrums. (1HM1)

In a very similar way to siblings, staff strategically managed their relationship with siblings to avoid conflict, as these comments illustrate.

We just don’t take it on board... as we are doing what we do in his best [resident brother] interests we try for his and everyone’s sake to keep in her [sister’s] good books. (6HM 2)... We never do things the right way. Learn to live with it... we don’t take it to heart. (6HM 1)

It’s a case of pick your battles. (2, 9M2)

Some staff adopted proactive strategies to educate families and begin conversations about difficult issues that were likely to be encountered in the future. For example,

We start to have the conversation to assist and facilitate the conversation to get to the point where it needs to be. (3,4,5,6, 10AM1)

Pushing the sister first because she didn’t really want to either. (15,18AM1)

Staff did not always agree with the stance taken by a sibling, and found different ways to impose their own view or deal with differences of opinion. This was sometimes done in an underhand rather than direct manner, meaning fundamental differences were not resolved. For example, staff members said:

If the family wanted them to go to church every Sunday and the client said no... we’d be following what the client said. (10HM1)

He very much wanted to go but his sister wasn’t keen on him going but the HM, in a nice way said that he should go (6HM1)... He has been fitted with a hearing aid. HM said that they hadn’t told her and would do so when they were fitted and he was used to them. (6HM4)

In one case staff had to manage differences between two siblings who were both involved with their brother who was resident in the group home. As the quotes below rather than try to mediate differing views staff made decisions about what they thought was in the resident’s best interests.

I was never actually informed about this until it was too late... I mean I was never actually informed of this until very late in the piece and so I hadn’t been consulted or advised of anything, just came like a bolt out of the blue, oh David’s going to America... Ester [second sibling] insisted he went on a diet, and I don’t think that was correct in the way that it was done, but the house were looking at it and they then put a stop to it and said David has lost enough weight and I think they took him to the doctor and got a clearance that that’s enough weight lost. (8F2)

Discussion

These findings demonstrate the close relationships that can continue between siblings with and without a disability into later life, and the longevity of family involvement in the lives of people with intellectual disability. They also show the separation of day to day ‘caring for’ by group home staff from the on-going and no less important ‘caring about’ by siblings who lived elsewhere. Some overlap between the care and support provided by staff and sibling was evident, for example in supporting residents to attend medical appointments and negotiations with formal systems. Yet, while staff do play a part in supporting social inclusion of residents, the type of inclusion work families do in terms of affirming a residents’ identity and their long term sense of belonging to a social group is unlikely to be replicated by staff. Thus the siblings in this study both supplemented staff roles, providing at
times similar care but also complemented it by providing something that was of a qualitatively different nature. Although there is no evidence to suggest that staff did not care about residents' well-being, they did not have the long term commitment that is present, irrespective of geographic separation that was evident in the relationships between the siblings in this study, and which Litwak (1984), suggests characterises relationships of close family members.

As well as highlighting the strong commitment of these siblings to fostering and safeguarding all aspects of the wellbeing of their brother or sister with intellectual disability, these findings illustrate that sibling relationships do not happen in a vacuum. Rather they are embedded in the daily operation of group homes, requiring significant interaction with staff and reliant on a partnership with them. The findings suggest there are few protocols in place to set the ground rules or guide staff in their relationship with families. This absence of systematisation or formalisation was dealt with by staff and siblings actively and strategically managing each other. For the most part the consequent relationship resembled an 'easy partnership', that had been implicitly negotiated to suit the particular preferences and circumstance of the sibling. These easy partnerships were characterised by trust, confidence, mutual respect, shared tasks and good communication. Notably these components reflect some of the seven dimensions that Turnbull et al., (2001) suggests should form the basis of partnership between professionals and families of children with a disability, which are; communication, professional competence, respect, trust, commitment, power equality and advocacy. These components may provide the basis for the development of principles to inform working relationships between families of adult with intellectual disability and staff in disability services. The data in this study illustrate the diversity of family service relationships, in terms of the frequency and intensity of contact siblings have with their resident brother and sister and the house, and their expectations about involvement in day to day decision making and the volume and detail of information they expect to be made aware of. This diversity indicates the significant challenge of attempting to codify or standardise family staff relationships.

The intermittent periods alluded to by siblings when partnerships with staff deteriorated, becoming strained and uneasy, suggest a need to introduce some guidance and uniformity to staff skills and expectations about relationships with the family members of residents. Siblings have long term contact with their brother or sisters' group home and the organisation that manages it, which had outlasted in many instances that of staff connections to both resident and the organisation. As staff and organisational regimes had changed so too sometimes did relationships with siblings, creating anxiety and a felt necessity to adjust involvement in their brother or sisters' life. The fluid and serendipitous nature of relationships with group home staff, had clearly been stressful and difficult for some siblings to manage. If, as suggested, the revised Federal standards for disability services include working with families it will be important for organisations to consider what is expected of family staff relationships, and how to ensure continuity across time for families members who have long term connections to a service such as a group home. But strategies would also have to find ways of building in flexibility to mould relationships to families' preferences and circumstances, as well as a capacity to adjust relationships to changes that occur with age and family constellations. This study has provided some insights into the nature of easy and uneasy partnerships between staff and families but further research is required to uncover the processes necessary to underpin and sustain easy and avoid uneasy partnerships.

The findings also draw attention to the more acknowledged long standing issue of who is the substitute for this type of relationships for older adults without involved siblings, which was captured by the words of one siblings who said, 'it makes you wonder what happens to those without family' This is a major challenge that confronts the reform of the disability system which will increasingly rely on consumer directed choice, in the form of the person with intellectual disability and those who know them well. There may be potential here to apply to those adults without strong family connections the concepts and learning's from the work that has been undertaken on the creation of intentional networks, circles of support or micro boards by resourceful families (Etmanski, 2000).

Finally these findings reiterate the current 'greyness' about the status of family members in decision making about their relatives' lives and the different expectations about this by different professions and service sectors. It seems too that clear pathways are not easily accessible to mediate conflicting views of family members and staff,
which can mean staff resort to disrespectful or underhand means of resolution rather than using more open and considered processes. Overall these findings point to the need for greater attention by service to staff family relationships and recognition of the unique contribution and long term commitment of some siblings to the wellbeing of their brother or sister with intellectual disability who live in a group home.

References


Productivity Commission. (2011). Disability Support and Care: Report no. 54 Canberra Productivity Commission


Family Engagement Project:
A Call for Change

Ron Tiffen & Anthony Kolmus

Office of the Disability Services Commissioner, Victoria, Australia.

Introduction
The Disability Services Commissioner (DSC) calls on the disability sector in Victoria to support the development and implementation of policy and practice aimed at improving relationships between service providers and the families of the people with a disability whom they support. Based on findings arising from over four years of operation, DSC believes that there needs to be an increased focus within the sector on establishing mutual expectations and agreement between service providers and families in relation to the provision of disability services. As discussed in this paper, DSC believes that doing so will result in increased levels of satisfaction and improved outcomes for people with a disability. This paper has also been informed by a series of ‘think tank’ consultations held in September and October 2011 with key stakeholders including service providers, family and carer groups, advocates, and academics.

Part One – DSC Mandate and Functions
The Disability Act 2006 (the Act) specifies functions and powers of the DSC that require us to:

• Review and identify causes of complaints and to suggest ways of removing and minimising those causes (s 16 (b))
• Consider ways of improving disability services complaint systems (s 16 (h))
• Provide training about the prevention and resolution of complaints relating to disability services (s 16 (o))
• Conduct research into complaints relating to disability services and mechanisms for resolving complaints relating to disability services (s 16 (p))

The Act also provides that in facilitating the resolution of complaints we seek to improve service delivery. We do this through a conciliatory framework, giving voice to stakeholders in the provision of disability services in Victoria.

Information and experiences that inform DSC’s practice and knowledge are drawn from all three areas of our operation as follows:

1. Sector monitoring and analysis of complaints
The Act requires all registered disability services in Victoria to report to DSC, through the Annual Complaints Reporting (ACR) process, on all complaints received in each financial year. In 2010/11 there was for the first time a 100% response rate by disability services. Whilst overall complaint trends reported by service providers are similar to data collected by DSC, one in three disability services reported zero complaint activity over the past four years. At DSC we estimate that less than 1% of people in with a disability (and/or their families) make complaints about the services they receive1.

2. Capacity development
DSCs Capacity Development (CD) Team, works directly with the disability sector to raise awareness about people’s right to complain and provide advice on improving the handling of complaints. In that task the team meets and consults with representatives of agencies, parent associations, service users, their family members, members of the community and advocates. DSC representatives also participate in forums and conferences in the disability sector.

In 2010, the Commissioner and staff at DSC travelled to all states and territories of Australia to speak to agencies that deal with complaints not only in the disability sector but also in health services and human rights. The importance of constructive engagement between families and agencies is not isolated to Victoria or to the disability sector. From our consultations we found that there is a call from many quarters for attention to the issue of the role of families in the provision of care.

3. Complaints and enquiries to DSC
The Assessment and Conciliation (A&C) Team respond to enquiries and complaints made to DSC. Over 2,300 enquiries and complaints have been received since the office was established in

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1. This figure is calculated on our estimate of the client numbers across Victoria. DSC does not have sufficient information to make a precise calculation but the strong assumption is that there is significant under reporting or that stakeholders are not prepared to complain.
July 2007. The Act provides that any person may make a complaint to the DSC. The jurisdiction of DSC is confined to complaints about the provision of services by a registered disability service in Victoria or about the way a registered disability service has handled a complaint.

Part Two – Findings

Complaints Data Collected by DSC

Commencing operation on 1 July 2007, DSC now has four full years of data from both our own experiences and those reported by service providers to inform our call for change in family and service provider engagement. (Please refer to our annual reports for a more extensive analysis of complaints data than appears here.)

Although the overall numbers of matters dealt with by DSC and reported by service providers have increased each year, the pattern of enquiries and demand reveal some particularly consistent trends in data as outlined below. The data outlined below is from the DSC 2010-2011 annual report and has, on the whole, been consistent through most of the past four years.

Source of enquires and complaints.

<table>
<thead>
<tr>
<th></th>
<th>DSC 2</th>
<th>ACR 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families</td>
<td>52%</td>
<td>55%</td>
</tr>
<tr>
<td>Service Users</td>
<td>23%</td>
<td>26%</td>
</tr>
<tr>
<td>Care/Support staff</td>
<td>12%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Types of services that are the subject of complaints.

<table>
<thead>
<tr>
<th></th>
<th>DSC</th>
<th>ACR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared SupportedAccommodation</td>
<td>37%</td>
<td>30%</td>
</tr>
<tr>
<td>Individual Support Packages 4</td>
<td>26%</td>
<td>13%</td>
</tr>
<tr>
<td>Day Programs</td>
<td>16%</td>
<td>22%</td>
</tr>
<tr>
<td>Case management</td>
<td>13%</td>
<td>8%</td>
</tr>
</tbody>
</table>

Types of disability of service users. 5

<table>
<thead>
<tr>
<th></th>
<th>DSC</th>
<th>ACR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability</td>
<td>66%</td>
<td>65%</td>
</tr>
<tr>
<td>Physical disability</td>
<td>43%</td>
<td>21%</td>
</tr>
<tr>
<td>Autism</td>
<td>30%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Common Themes Arising in Complaints to DSC

The majority of complaints made to DSC have multiple complexities which include disputed interpretation of facts, policies and rights along with a history of poor communication, broken trust, emotional frustration and exhaustion. Where there is escalating conflict we find that all parties in the situation may suffer. Each side attribute negative personal qualities to the other and person-centred planning may stall as decision making is frustrated and energies are directed at the conflict rather than the task of promoting good support for the person who the complaint is intended to assist. In some instances family members and care/support staff have mentioned to DSC that they have sought assistance for stress and anxiety. Where frustrations escalate some families have taken their family member out of a service as a way of resolving the issues.

DSC’s experience over the past four years has found that where families and service providers engage in discussions that explore expectations and acknowledge the differences in understanding of roles and responsibilities, disputes can be resolved even where they seem intractable. DSC’s resolution rate has increased steadily over this time, with 70 per cent of complaints being fully or substantially resolved in 2010-2011, with a further 12 percent partially resolved.

Key issues observed by DSC that arise specifically in relation to the relationship between families and service providers include:

Fear.

Despite the promotion of DSC’s message that “It’s OK to Complain” and the increasing numbers of people raising issues with their service provider or DSC, many families and people with a disability still state that they are afraid to voice their concerns to the service providers whom they rely on to provide care and support.

They fear retribution, loss of service and loss of relationship with services that are valued. Many believe that making a complaint is to cross a line in the sand with the service provider that will change the relationship permanently.

2 The DSC figures are those enquiries and complaints that are made directly to DSC.

3 The ACR figures are complaints (not including enquiries) made to service providers and reported to DSC as part of the legislative requirement for all registered service to report annually on their complaint activity.

4 Enquiries and complaints about Individual Support Packages are increasing at a rate consistently higher than other service types. At least in part, it is likely that this correlates with the increasing number of ISPs now available to people.

5 Note – The percentage figures exceed 100% as many service users have multiple disabilities.
Given the fear that clearly exists amongst people with a disability and families, we urge the sector not to rest on the assumption that low rates of complaints are entirely due to high rates of satisfaction with service provision. Further, and in the context of delivering person centred supports, we urge service providers to consider improved relationships with families as one of a suite of strategies that should be adopted to reduce people’s fear of speaking up about their supports.

**Recognition of families and natural supports.**

Few people in society would dispute that family, friends and other natural supports are typically an important part in people’s lives. In spite of issues that can sometimes arise, for the vast majority of people it is these relationships that are often the key to our sense of identity, overall wellbeing and general satisfaction with the life we lead. It is no different for people with a disability. Indeed, it could be argued that for people with a disability, who often experience higher levels of social isolation than is typical in the general community, the involvement of family and other natural supports becomes even more important. As indicated in DSC’s complaints data (see Part 2 above), the majority of people who are the subject of complaints to DSC and service providers have an intellectual disability. As a result they may have difficulty speaking out about any concerns they might have about their supports. In this context, the role of families and other natural supports in advocating for the rights and well-being of people becomes critical. Without such support, many people with an intellectual disability would be without anyone other than their service provider to look out for their day to day well-being and rights.

In recognition of these roles that families and natural supports play in people’s lives, the Act requires disability service providers to consider, respect and acknowledge the role of families in supporting people with a disability and where possible strengthen and build their capacity [section 5(3)(h)(ii)] & (k)]. The Quality Framework for Disability Services in Victoria (2007) also requires that disability providers have in a place a **Working with Families** policy that guides their approach to working with the families of the people they support.

In practice, DSC has found few examples of service providers having have such a policy in place. Whilst there are many good examples of co-operative and respectful relationships between service providers and families, the lack of a documented approach to this area of service provision often results in practice being dependent upon the attitudes and practices of specific individuals within organisations rather than a planned and considered approach by organisations as a whole.

**Differing expectations between families and service providers.**

Many issues brought to DSC arise specifically as a result of differing expectations between service providers and families in relation to anticipated levels of communication and consultation. As discussed earlier, the lack of a planned approach by service providers to working families can result in inconsistent experiences for families within organisations and variations in practice when staff change. When combined with a lack of conversation and agreement between service providers and families as to their expectations of each other in relation to levels of communication and consultation, these factors can all contribute to an increased incidence of differing expectations and subsequent disputes.

It is our experience that these scenario’s are often the basis of matters brought to DSC and, in our opinion, have the potential to detract from the quality of the supports being offered.

**Part Three – The Call For A New Conversation Between Families And Service Providers.**

Although DSC is calling for changes in aspects of the engagement between families and service providers, we recognise that at a broader level there are many examples of strong engagement between families and service providers in the disability sector. Many agencies have family member participation at Board level, on quality advisory groups and in fund raising. Families have been pioneers in service development in Victoria and many service providers can point to a wonderful record of achievement in including families in their planning and service provision. Many services owe their existence to the work of families.

As previously indicated, where difficulties arise in relationships between families and service providers, they are most commonly caused by differences in expectation about the level of communication and consultation that will occur.
Based on DSC’s observations across the capacity development, enquiry and complaints functions, we call for the creation of a clearer set of policy and practice guidelines that not only recognises the importance of family in the lives of people with a disability, but also focusing on the issue of supporting people with a disability within the context of their family and other natural supports.

Whether as part of a broader Working with Families policy or as a stand alone document, DSC also calls for an increased emphasis by service providers on taking a lead role in initiating agreements with people’s families and other natural supports to achieve mutual and agreed expectations of each other in relation to communication and consultation.

DSC suggests that the conversation between service providers and families should be developed within a person centred framework and consist of four parts as follows:

1. **New Conversation – First Part:**

*Translating principles (of the Act) into a service approach for the individual.*

Frequently we find that families and service providers are at odds about what should occur for the person who is being supported, and this in turn is connected to the fundamental understandings about how these principles are translated into practice. A common issue is the aim to promote independence and choice for a person. Families may dispute the basic direction of the service. The aspirational aims of the service provider may look like a risk to the family. These issues may undermine the service delivery and need to be addressed early in the provision of service.

2. **New Conversation –Second Part:**

*Clarifying mutual expectations and responsibilities between the service provider and the family.*

From a complaints perspective the conversation and agreement needs to address at least four issues that are frequently the source of dispute and complaint between service providers and families, they are:

1. The provision of information between service providers and families. Each has access to information and each needs access to information. The issue is what is reasonable to expect and what the purpose of the provision of the information is. It is also important to establish the best means of communicating.

2. The respective roles in planning for the person who is being supported.

3. The respective roles in implementing plans and generally supporting the person with a disability.

4. The respective roles in decision making around the support needs and life choices of the person with a disability.

DSC’s experience has shown that where families and service providers engage in discussions that explore expectations and acknowledge the differences in understanding of roles and responsibilities, disputes can be resolved even where they seem intractable. We believe that having these conversations during the development of the disability supports to be offered would significantly reduce the likelihood of future disputes and/or provide information that may assist in the resolution of any disputes that do arise.

3. **New Conversation- Third Part:**

*Responding to adverse events and crises.*

Where the person who is being supported by the service provider is subject to an adverse event or a crisis in care arises, the family needs a different set of arrangement to the normal in terms of provision of information, briefing and support. Some families have spoken to DSC in terms of being ‘traumatised’ as a consequence of injury to their family member but the trauma is said to be magnified by the actions of service providers where they appear to ignore the family in the response to an adverse event. The purpose of contacting the family about an adverse event also needs to be clear, as to whether it is to provide information or to engage the family in providing support to the person affected.

4. **New Conversation – Fourth Part**

*Agreeing on what to do when we do not agree.*

Things can go very wrong when families and service providers have no ground rules and agreed process for communication and behaving in the situation where either becomes dissatisfied even distressed by the behaviour of the other. Dispute resolution systems work best if the parties have designed them before a dispute arises.
Part Four – Realising the Call for Change

DSC’s proposed approach includes five component strategies, which we envisage would be overseen by a Reference Group to guide the approach:

1. Surveying the disability sector to highlight the many initiatives around including families.
2. Policy development that better articulates the roles and responsibilities of families in relation to service provision in the disability sector.
3. Developing a set of criterion for the use of service providers and families to guide their discussions and establish a documented agreement as to expectations and responsibilities.
4. A literature review of research and descriptions of family relationship building with service providers in the disability service area.
5. Consult and explore the numerous related developments in the policy context of guardianship/assisted decision making, circles of support, supportive environments etc.

We believe that the disability service providers and families will make the new conversations and subsequent agreements work best where they can adapt them to their particular service and needs. This in turn can best be progressed through an action research approach and DSC proposes to invite a few service providers to trial the idea of the ‘new conversations’ with families. The ideas outlined here are in their formative stage and DSC welcomes comment and debate at the Policy Roundtable.
Supported Decision-Making for People with Severe or Profound Intellectual Disability: ‘We’re All in This Together, Aren’t We?’

Jo Watson, Scope and Deakin University

Those Rarely Heard: People with Severe or Profound Intellectual disabilities

This paper aims to explore understandings and practices around decision-making for people with severe or profound intellectual disability. In doing so, it draws on key literature regarding the needs of this group and their ongoing reliance on their supporters to live lives they prefer. Rejecting the notion of individualization within decision-making processes, this paper seeks to re-conceptualise decision-making as a collaborative interdependent venture.

The conceptualization, classification and terminology surrounding intellectual disability (ID) has varied over time, ranging from a strong emphasis on human defect (Grossman, 1973) to a more modern ecological perspective (Amos, 2004; Mirenda, Iacono, & Williams, 1990), which emphasizes the role that environmental/contextual factors such as participation, support and interactions play on the condition of ID. Bronfenbrenner, in his work examining the ecological impact of human development generally (Bronfenbrenner, 1979), has influenced the paradigm shift within the field of disability (Sontag, 1996). This more ecological focus is consistent with other aspects of an emerging disability paradigm generally that is challenging older conceptions of what is meant by disability (Fujiura, 2004). The World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) framework reflects this ecological focus (World Health Organisation (WHO), 2001). Parmenter and Arnold (2008) emphasize WHO’s measurement and categorization of disability in terms of the level of limitations to activities, barriers to participation and levels of support needed (Parmenter & Arnold, 2008).

Drawing from this ecological perspective, people with severe or profound intellectual disabilities can be characterised as those who are highly dependent on others for support in most aspects of their lives, including communication and decision-making. They generally communicate informally, as they have difficulty understanding formal communication such as speech, sign, written word, pictures or photos. Many people with severe or profound intellectual disabilities communicate unintentionally. This means that there is an additional onus on communication partners to infer meaning from a person’s behaviours.

Interpretation: A Challenging Responsibility

Grove and colleagues highlight the challenges of interpretation, describing people with severe or profound intellectual disabilities as having a high level of “dependence on the interpretations of others to make themselves understood which often leads to ambiguity of meaning” (Grove, Bunning, Porter, & Olsson, 1999 p.190). They highlight the difficulties of interpretation stating that people with severe or profound intellectual disabilities have ‘an inability to contradict an interpretation and tell you ‘No, that’s not what I meant’ (Grove, et al., 1999 p.190). Grove’s point regarding ambiguity around communicative agency is a vexing one. People with severe or profound intellectual disabilities, by the very nature of their disability, are dependent on the involvement of others to act as advocates, facilitators or interpreters, sometimes referred to in the literature as proxies (McVilly, Burton-Smith, & Davidson, 2000; Stancliffe, 1999). This reliance inevitably begs the question of ownership of the message. In this situation, interpreters are bound to rely on inferences based on the context, and their prior knowledge of the person. An obvious risk, expressed within the literature, is that the meaning assigned to the communication may reflect the hopes, fears and desires of the interpreter rather than those of the person with a disability or it may simply be inaccurate (Carter & Iacono, 2002; Grove, et al., 1999).

Sustaining this concern, research has generally reported relatively poor concurrence between direct preference assessment and proxy views (Parsons & Reid, 1990; Rapley, Ridgway, & Beyer, 1998; Reiter & Bendov, 1996; Windsor, Piché, & Locke, 1994). It is clear that reliance on one person to ‘speak for’ someone is fraught,

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1 Thanks to the following colleagues for their contribution to this paper, Dr Erin Wilson, Deakin University, Dr Nich Hagliassi, Scope and Michael Bink, Scope. Thanks also to the Office of the Senior Practitioner, Department of Human Services Victoria for the provision of a PhD scholarship to Jo Watson which has partially funded some of the research presented in this paper.
with serious questions around whose voice is being broadcasted. Obtaining and interpreting the preferences, interests and wants of people with severe or profound intellectual disabilities is difficult and challenging. However, researchers and practitioners interested in decision-making and choice for people with severe or profound intellectual disabilities are faced with a quandary. As Petry and colleagues point out, they have a choice, 'Either ignore these individuals because they cannot self report, or obtain data from proxies that may be biased or invalid' (Petry, Maes, & Vlaskamp, 2009 p.1327). Perhaps rather than questioning whether proxy reports should be used, we should accept that their use is inevitable in many cases and therefore the question that should be asked is how and by whom are the person’s preferences obtained, interpreted and shared.

The Importance of Relationships for People with Severe or Profound Intellectual Disabilities

Due to the heavy reliance that people with severe or profound intellectual disabilities have on others to have their preferences heard, the importance of positive trusting relationships, particularly within the context of decision-making, cannot be underestimated. The fundamental importance of relationships, whether they are with family, service providers or others within the community, for people with severe or profound intellectual disabilities is increasingly being highlighted within the literature. A number of authors suggest that people with severe or profound intellectual disabilities, due to the nature of their disability, are more in need of positive interpersonal relationships than anyone else (Grove, et al., 1999; Kennedy, Homer, & Newton, 1989; Seltzer & Krauss, 2001). Although not focusing specifically on people with severe or profound intellectual disabilities, Jennifer Clegg (2009) eloquently expresses the importance of relationships for people with ID generally: ‘Despite the centrality of autonomy to neoliberal cultures, people with intellectual disability, like everyone else, need to live in relationships. They require help to manage their daily lives and to express themselves through various roles and activities, but they also want and need acceptance, concern, warmth, understanding and companionship. With such relationships in place, daily life becomes more possible for all of us. Without them life can become seriously impoverished: health and well-being may deteriorate, the practicalities of living may become problematic and life may get increasingly lonely, frightening and without point’ (Clegg, 2009a p.12). Unfortunately, despite this increasing acknowledgment of the need for trusting and supportive relationships in the lives of people with ID, the reality is they typically have small, highly restricted social networks limited to interactions with other people with intellectual disability, family members, and paid workers (Forrester-Jones et al., 2006; Lippold & Burns, 2009). Moreover, for people with severe or profound intellectual disabilities, this social network is likely to be even smaller than their less intellectually disabled peers (Bigby & Clement, 2009; Krauss, Seltzer, & Goodman, 1992). Of particular concern is the finding by Clement and Bigby (2009) that circles of support often see people with severe or profound intellectual disabilities as ‘too different’ from the rest of the community to form relationships with (Bigby & Clement, 2009).

The Expression of Preference

As already discussed, obtaining and interpreting the preferences, interests and wants of people with severe or profound intellectual disabilities is difficult and challenging. Perhaps the answer lies in the process by which preferences are obtained and interpreted. It is worth noting here that much of the focus around preference assessment to date has been on the opinion of a lone assessor (Parsons & Reid., 1990; Rapley, et al., 1998; Windsor, et al., 1994) who may not necessarily know the person well. The literature has paid little attention to the value of carrying out such assessment in a collaborative manner by a group of people who have positive trusting relationships with the person with severe or profound intellectual disabilities, as characterised by a supported decision-making approach. This group of people has been referred to as a circle of support (Community Living Project Inc., 2011; Exceptional Children's Assistance Center., 2011).

Who is Doing the Supporting?

With the significant changes seen in the last forty years in relation to where Australians with intellectual disabilities live, there has been a need to redefine who may form a person's circle of support. For some, although not all, deinstitutionalization has brought with it increased contact with family and friends (Emerson & Hatton, 1996; Tabatabainia, 2003; Young, Sigafoos, Sutje, Ashman, & Grevell, 1998). For a proportion of people with severe or profound
Family Centered Practice: Does it Have a Role in Adult Based Services?

Family-centred practice has been a central philosophy of early childhood intervention in Victoria for two decades and it is firmly embedded within current policy and practice for Victorian children (State Government of Victoria, 2009). There is little argument that disability impacts on the entire family of which the child is a part (Turnbull, Turnbull, Erwin, & Soodak, 2006), that children are best served within the context of their family life (Craft-Rosenberg, et al., 2006; Moore & Larkin, 2004), and that services working in partnership with families are better able to meet the needs of a child with a disability (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Dunst, 1997). Turnbull et al. (2000) refer to effective family centred practice as a form of ‘collective empowerment’, whereby mutually desired outcomes are most likely for the child with a disability when, the child themselves, family members, professionals and community members work collaboratively without taking power from each other (Turnbull, Turbiville, & Turnbull, 2000 p.641). Within Victoria, once a child with intellectual disability reaches adulthood, service provision is provided by the adult disability sector. Adult disability services within Victoria are primarily characterised by person centred approaches, which, in contrast to child based services, place less emphasis on the role of family in the lives of someone with an ID (Department of Human Services, 2002; Parmenter & Arnold, 2008; State Government of Victoria, 2006, 2008; State Government of Victoria, 2007). Although such a refocus is likely to be welcomed by many families and people with disabilities who are ready to further embrace all that an adult/independent life has to offer, it can be particularly problematic for people with severe or profound intellectual disabilities, whose interdependent relationships with their families are not likely to change (Beresford, 2004; Bhaumik et al., 2011; Blacher, 2001; Hudson, 2003). People with severe or profound intellectual disabilities generally do not cease being dependent once they turn eighteen, and therefore the notion of ‘collective empowerment’ characteristic of effective family centered practice, described by Turnbull and colleagues (2000), is likely to continue to be relevant into adulthood for this group of people.

Self Determination for People with Severe or Profound Intellectual Disabilities: A Myth?

The self-determination movement has been responsible for one of the most important paradigm shifts in the field of disability over the past two decades. This movement has focused on increasing the independence of people with ID, with the view that the more independent someone is the more likely they are to live self determined lives and to have a better quality of life (Kennedy, 2001; Wehmeyer & Schwartz, 1998). The right to make one’s own decisions is viewed as an inalienable right by Australians with disabilities, and yet only relatively recently has the concept of self-determination been considered for adults with severe or profound intellectual disabilities. A review of the literature reveals that many, including people supporting those with severe or profound intellectual disabilities, believe that self-determination is not a relevant concept for this group of people (Singer, 1993; Brown & Gothelf, 1996; Stancliffe & Abery, 1997; Wehmeyer, 1998). There are concerns that in a time when many people (including those with disabilities) have more opportunities to control their lives than ever before, people with the most severe and profound intellectual disabilities are being left behind (Smith, Morgan & Davidson, 2005; Emerson & Hatton, 1996; Hatton et al., 2004). A discussion of the many reasons for this exclusion is beyond the scope of this paper; however, one theory worth exploring is related to the conceptualization of self-determination within a western cultural context which may not sit well with the needs of people with severe or profound intellectual disabilities.

Conceptualizations of self-determination that are individualized in orientation (Schwartz, 2000;
Wehmeyer, 1992) are increasingly being challenged within the literature and practice (Burton Smith, Morgan, & Davidson, 2005; Felce et al., 1998; Hatton et al., 2004; Pepin, Watson, Hagiliassiss, & Larkin, 2010; Stalker & Harris, 1998; Watson & Joseph, 2011c). This literature argues that in order for the concept of self determination to be relevant to people with severe or profound intellectual disabilities, and those who know and love them, concepts such as autonomy and decision-making competence should be redefined to better reflect the realities for this group of people, who by the very nature of their disability cannot live independent lives (Ramcharan, Roberts, Grant, & Borland, 1997). Simply put, people with SEVERE OR PROFOUND INTELLECTUAL disabilities have to depend on other people.

Of particular relevance to people with severe or profound intellectual disabilities is the literature's focus on the role of others, particularly family, in decision-making within non-western based cultures. The work of cross cultural researchers and theorists may further shed some light on the task of re-conceptualizing self-determination specifically for people with severe or profound intellectual disabilities (Bandura, 1989; Iyengar & Lepper, 1999; Jordan, 1991). The type of values that are prevailing across cultures can vary, and this is particularly the case in terms of how self determination is perceived. Whereas uniqueness, and independence are at the centre of societies perceived as individualistic, such as those found in the western world, relatedness and interdependence, and consequently the concept of collaborative decision-making, are highly valued in collectivistic societies, such as those found in many eastern cultures (Iyengar & DeVoe, 2003; Markus & Kitayama, 1991). A western view of self determination predominately emphasizes individual intellectual 'capacity' and explicitly excludes the vital contribution social and environmental factors make to a person's decision-making (Bach & Rock, 1996; Wehmeyer, 1998). This western view appears to be based on specific definitions of autonomy, self-determination and decision-making competence rooted in a 'disjoint model of agency' as described by Markus and Kitayama (2003). A disjoint model is one by which the self is constructed as 'an independent essence that is bounded within the individual and disconnected from others' (Markus & Kitayama, 2003 p.5). In contrast, in a conjoint model of agency, 'the self is understood as the presence of interdependent selves in relation to others and is affirmed through harmonious relationships with in-group members and meeting social norms' (Markus & Kitayama, 2003 p.5). The value of this interdependent approach, central to many eastern societies, is examined and supported by cross cultural researchers and theorists (Bandura, 1989; Iyengar & Lepper, 1999; Jordan, 1991). Iyengar and Lepper (1999) in particular, characterize autonomy in a way that suggests that individualized autonomy is generally a western post modern construct and is not generally coveted in more 'socially interdependent cultures' or collectivistic societies, such as found in Asia, Africa and in some parts of Europe (Iyengar & Lepper, 1999, pp. 349-366). They describe a more collective view of autonomy in these cultures, whereby optimal decision-making is seen as more of a collaborative rather than an individualized process. Within these cultures decisions are usually made within the context of families and communities, supporting the view that self determination and decision-making do not require independence or independent 'competence' but can rely on and involve others in a collaborative way. This perspective offers a way for people with severe or profound intellectual disabilities to achieve some measure of self determination, and is found at the heart of a supported decision-making (SDM) approach.

A Re-Conceptualisation of Self Determination for People with Severe or Profound Intellectual Disabilities

For people with severe or profound intellectual disabilities, the non-western view of autonomy and decision-making highlighted by cross cultural researchers may be particularly relevant. Optimal decision-making for people with severe or profound intellectual disabilities is increasingly being characterized by a collaborative effort influenced by the person themselves and ultimately made by those in their lives who know and love them. If the conclusions of cross cultural researchers, like those of Iyengar and Lepper, are accurate, perhaps those considered vulnerable decision makers could benefit from the guidance of those cultures considered more 'socially interdependent'. For the purpose of this paper, self determination is characterized in this way, whereby the value and contribution of collaborative/supported decision-making is not only emphasized but promoted. Rejecting the concept of individualization within decision-making processes, it will draw on the psychological need, proposed by self determination theorists (Deci & Ryan, 1985), for interpersonal-relatedness...
or belongingness. Such a view is supportive of a collectivist and interdependent view of decision-making, a view that has clear relevance to those who, by the very nature of their disability, are required to live interdependent, as opposed to individualistic, lives. For these people autonomy is not, nor will it ever be, an individualised concept.

There is expanding support for the value of such a collectivist approach to decision-making in the lives of people with intellectual disabilities. Codling and MacDonald (2011), in their recent research evaluating the delivery of health care to people with ID in the United Kingdom, concluded that people with ID achieve and maintain good health by relying on the support of others to meet their needs (Codling & Macdonald, 2011). Aznar and Castanon (2005) focused on the quality of life of families in Latin America who had a member with an ID (Aznar & Castanon, 2005). Their work supports research previously discussed (Clegg, 2009b; Grove, et al., 1999; Seltzer & Krauss, 2001) highlighting the importance of trusting relationships for people with severe or profound intellectual disabilities particularly within the context of families.

Fyffe et al. (2010) suggest that policies that separate the needs of carers from those of people with disabilities fail to recognize the interdependent nature of this relationship (Fyffe, Pierce, Ilsley, & Paul, 2010). They describe the lives of people with disabilities, particularly people with severe or profound intellectual disabilities, and their supporters as intertwined, rather than using separate conceptualizations about those who have a disability and those family members and friends who support them. Despite this, Fyffe et al (2010) suggest that current Australian community living policy and service responses increasingly pit the needs of carers against the needs of people with a disability in funding priorities to ‘no advantage of either group’ (Fyffe, et al., 2010 p.7). They suggest that the clash of priorities from the two perspectives has become embedded in policy practice and legislation and they propose a more integrated strategy. Supported decision-making is one approach that adopts such an integrated strategy particularly within the context of decision-making.

**Supported Decision-making (SDM)**

Challenging the notion of decision-making competence, a SDM approach assumes that if people are supported to participate in decisions, then they are more likely to lead lives they prefer. This approach recognizes the value of collaborative decision-making particularly for those with severe or profound intellectual disabilities. It is worth noting that this dependence is not necessarily qualitatively different from what people without ID experience. There is growing acknowledgment for the notion that all people are dependent on others, and that ‘this dependency is part of the social nature of human life’ (Kennedy, 2001 p.2). Examples of this interdependency are visible in all aspects of human life. Although we highly value personal independence, the fact is that we are highly dependent on each other for success.

Today, supported decision-making (SDM) is found at the centre of discussions around guardianship reform both here in Australia and internationally. The Victorian guardianship legislation (State Government of Victoria., 1986) is currently under review. Documentation around this review, drafted by the Victorian Law Reform Commission, places supported decision-making firmly at the centre of their proposed reform. This document describes supported decision-making as follows: ‘Supported decision-making emphasizes the interdependent nature of most people’s lives. The important decisions we all make are often made with personal support (such as advice from family, friends or mentors) or perhaps professional support (for example, lawyers or accountants). Some people with disabilities may simply need additional support to make decisions’ (Victorian Law Reform Commission., 2011 p.116). Scope’s submission to the Commission (Watson, 2010a), describes the notion of supported decision-making as guided by the following principles:

- Everyone can participate in decisions with support;
- Everyone has responses to things they experience. These responses are often interpreted as preferences by people who know someone well. These preferences can be used as the building blocks of decisions;
- There is significant value in human beings supporting one another to make decisions;
- Everyone uses their support networks in making decisions that are difficult for them.

(Watson, 2010a p.15)

Supported decision-making principles such as those outlined above are gradually appearing in adult guardianship legislation across the globe, with Canada largely taking the lead (Gordon, 2000) and Western Europe following close behind (Blackman, 1997). Focus on Supported Decision-
making in more recent times has largely been driven by the United Nations Convention on the Rights of Persons with Disabilities (2006), which is strongly supportive of this approach as a viable alternative to court-ordered guardianship. Article 12 of the Convention has contributed to a paradigm shift in the way those with intellectual disability are perceived in terms of their capacity to make decisions (United Nations, 2006). Supported decision-making, as enshrined in the United Nations Convention, starts from the full and equal legal capacity of all citizens, including those with severe or profound intellectual disabilities. From this premise it then stipulates the right of everyone to receive appropriate support in decision-making. Carter in her recent paper ‘Supported Decision-making: Background and discussion paper’ states ‘Guardianship in Australia has, under the Guardianship and Administration Act 1986, been conceptualized as a last resort with a guardian appointed only when less restrictive options have failed or are not available. For guardianship to properly be a last resort there must be an adequate first resort. The United Nations Convention establishes supported decision-making as the first resort: the preferred alternative and, where necessary, precursor to guardianship’ (Carter, 2009 p.3).

Despite Supported decision-making (SDM) being found at the centre of guardianship reform both here in Australia and internationally, there is a dearth of empirically based research validating this approach. Additionally, to date there is no consistent definition of SDM within the literature. However, there is a general consensus within policy and practice based literature that SDM is underpinned by one basic principle, that being, a person’s ability to make a decision should not only be related to their level of individual cognitive capacity, but perhaps more importantly, to the degree of support available to help them make this decision (Bach, 2007; Brayley, 2009; Carter, 2009; Pepin, et al., 2010). Supported splices little emphasis on individual decision-making capacity, and more of an emphasis on the value of collaborative supportive decision-making processes (Pepin, et al., 2010). It acknowledges that, in a contemporary world, a person’s ability to make a decision should not only be related to their level of individual cognitive capacity but perhaps more, to the degree of support available to help them to make this decision (Pepin, et al., 2010). A quote by Beamer and Brookes (2001) from Values in Action, an organization in the UK, eloquently expresses this view, particularly in relation to people with severe or profound intellectual disabilities. The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices’ (Beamer & Brookes, 2001 p.4). In referring to supported decision-making, Gordon argues that, ‘The concept simply recognizes the way in which most adults function in their everyday lives. It is argued that independent decision making is a myth; that every adult uses interdependent decision-making in the course of getting through the day’ (Gordon, 2000 p.99).

Scope has developed a supported decision-making resource specifically for people with severe or profound intellectual disabilities and their supporters (Pepin, et al., 2010; Watson & Joseph, 2011c). This resource is centred around a framework (Watson, 2010b) designed to gather a consensus view on what a person with severe or profound intellectual disabilities may be communicating and/or what is in their best interests and from there make a decision. It guides circles of support (including family members, support workers, and others) through a process of supported decision-making focusing on a particular decision the person they support is facing. The framework recognizes that the role of a supporter is a highly responsible one, requiring an understanding of the person and their preferences, and a desire to respect the dignity of the represented person, who might be particularly vulnerable. Moreover it recognizes that the supporting of someone to participate in personal decisions is open to abuse, and therefore strives to reduce such potential by ensuring that the process is as transparent, honest and collaborative as possible (Watson & Joseph, 2011a, 2011b, 2011c). Also, the fact that there is a reliance on a circle of support rather than a single individual functioning as a proxy decision maker, helps ensure that there is a balance of viewpoints represented in decisions affecting the person. The resource is currently being evaluated as part of a PhD project being undertaken by Jo Watson through Deakin University and funded by the Victorian Government’s Office of the Senior Practitioner. The framework is characterised by 5 key phases which are displayed in Figure 1.
The Impact of a Supported Decision-making Approach on People with Severe or Profound Intellectual Disabilities and their Families: Preliminary Research

Scope has engaged in preliminary research designed to ascertain the impact of its supported decision-making approach and framework on the lives of people with severe or profound intellectual disabilities and those who support them. A detailed discussion of the findings relating to this research is premature; however, some themes are emerging from the data which will be briefly discussed within this paper.

Scope’s supported decision-making resource and framework was piloted over a period of six months with two circles of support and the person they care for/about. Both these circles of support were made up of family members and paid support staff. The information which has been collected during this pilot primarily includes narrative data collected during interviews and training sessions with circles of support, the video and audio transcriptions of which are in the early stages of analysis. This data is predominately related to the participants’ experience of supporting the focus person through a process of decision-making, using Scope’s SDM approach. Some broadly consistent themes have emerged from this preliminary data, three of which will be briefly explored. A more detailed thematic analysis of this data is yet to take place, and therefore it is suggested that the reader take this into consideration and view this preliminary data with caution.

The remainder of this paper focuses on three themes that have emerged from the data; all related to the factors believed to contribute to the successful functioning of a circle of support during a process of supported decision-making.

Theme 1: The importance of listening to those who know the focus person well, particularly families

The circles of support within this study clearly expressed the interdependent nature of the relationships they have with the focus person. One focus person’s mother said ‘they’re the ones that tend to be forgotten because they don’t have that ability to say what they want, so they rely on either their parents or their carers or people who work with them to tell other people what they want’ (Focus person’s mother).

Participants felt that there was a need for circles of support to listen to each other, particularly to families. Families reported that this was not always the case. As one parent reported, ‘this is where the issues are coming up all the time; people aren’t listening to us and what we know he needs. Hopefully after all this (the service) might listen, that’s what I am hoping anyway’ (Focus person’s mother).

Theme 2: The importance of knowing the focus person from all aspects of his/her life

The importance of knowing the focus person across all life areas is a consistent theme emerging from this preliminary data. One support worker stated: ‘We need to be part of every part of his life. If we spend time with him at home, we get to know how things happen there and don’t see him in isolation’ (Support worker). In addition to knowing the person across all aspects of their present lives, participants stressed that a person’s history and past life stories are also important. Within the context of claiming that the staff who work for her know the focus person well, a house supervisor stated: ‘There’s history, there’s longevity, they know people’s stories, and we don’t have a lot of casuals, who can’t know what he needs’ (House supervisor). A support worker said, ‘For the staff in our house there is history. They know where the guys have come from. When all this history is pieced together we get a better picture of someone’ (Support worker). One participant’s mother, in referring to a decision about where to go on a family holiday, drew from a story in the past: ‘We wouldn’t take her to the snow, she hates being cold, after being caught in the snow once, we know that she hates the snow’ (Focus person’s mother). Another focus person’s father said: ‘We used to take him up to Echuca with us, we used to have a caravan up there, sort of thing, we used to like going in the speedboat, used to sit him in the speedboat, he would be
relaxing, like he'd get excited with the water splashing that sort of thing. He might be like me; I'm a bit of a speed freak' (Focus person's father).

**Theme 3: The importance of open and transparent collaboration**

Participants (families and paid support workers) spoke about the value of circles of support working together in an honest and transparent way to achieve the best outcome for the focus person. A family member said: ‘it’s all about transparency; we need to be true and honest with each other. We’re all in this together, aren’t we?’ (Focus person's father). One support worker acknowledged the impact of the SDM approach on her view of collaboration: ‘I didn't realize how important it was for all of us to work together’ (Support worker). In response to this statement another support worker said: ‘We do try and work together. We have a group called “people we support in common”’ (Support worker). A support worker within a day service in referring to the importance of teamwork said, ‘Everybody just helps everybody, so we’re very lucky here’ (Support worker).

**Conclusion**

People with severe or profound intellectual disabilities can be characterised as those who are highly dependent on others for support in most aspects of their lives, including communication and decision-making. They generally communicate informally and sometimes unintentionally, relying heavily on the interpretation of others to have their preferences heard. Many, including people supporting those with severe or profound intellectual disabilities, believe that self-determination is not a relevant concept for this group of people (Singer, 1993; Brown & Gothelf, 1996; Stancliffe & Aber, 1997; Wehmeyer, 1998). This paper has argued that a primary reason for these views is related to western misconceptions of self determination as an individual/independent phenomenon. The paper argues that in order for the concept of self determination to be relevant to people with severe or profound intellectual disabilities, concepts such as autonomy and decision-making competence should be re defined to better reflect the realities for this group of people, who by the very nature of their disability cannot live independent lives.

Supporting the views of Fyffe et al (2010) this paper calls for a shift in policy and practice for this unique group of people, from one that emphasizes independence to one that better acknowledges the interdependent/collaborative nature of decision-making, particularly for people with severe or profound intellectual disabilities. Supported decision-making is offered as one vehicle which may play a role in this shift in policy and practice.

This paper has presented some preliminary data from an ongoing PhD study investigating the value of a specific supported decision-making approach developed by Scope (Pepin, et al., 2010; Watson & Joseph, 2011c). From this preliminary data several themes have emerged each of which are considered useful by those supporting people with severe or profound intellectual disabilities to participate in decisions. These themes include the importance of listening to those who know the focus person well, particularly families; knowing the focus person from all aspects of his/her life; and, open and transparent collaboration.

Although preliminary, this data provides some useful insights into the value of circles of support working collaboratively with people with severe or profound intellectual disabilities and with each other. This data lends weight to the argument proposed by Fyffe et al (2010) that policy and practice that over emphasize the importance of independence for people with severe or profound intellectual disabilities should be avoided. It is time that legislators and policy makers better acknowledged the reality for this unique group of people, that is, that without the support of trusted others they are unable to live lives that are self-determined. Scope's supported decision-making framework (Watson, 2010c) is offered as a tool for not only practitioners but policy makers and legislators who are committed to ensuring people with severe or profound intellectual disabilities are supported to participate in decisions that affect them.

**References**


On the Horizon: Policy Developments Concerning People with Intellectual Disability

John Chesterman, Manager, Policy and Education Office of the Public Advocate (Vic)

Introduction

In addition to our general systemic advocacy role, the Office of the Public Advocate (OPA) has involvement in the lives of people with intellectual disability via a number of our program areas. OPA’s Community Visitors regularly visit the supported residences and group homes where many people with intellectual disability reside. Over 5,000 visits were conducted by over 300 Community Visitors in 2010/11. Of these visits, there were 2,782 visits in the ‘disability services’ stream to residences where a significant number of people with intellectual disability live (OPA 2011a, p. 10).

In the same period OPA’s Independent Third Persons, of whom there are now more than 220, attended almost 2000 police interviews of people with apparent cognitive impairments or mental ill health (OPA 2011b, p. 30).

OPA runs a small program where staff attend internal prison disciplinary hearings involving prisoners with intellectual disability. In the last reporting period 136 hearings were attended (OPA 2011b, p. 30).

OPA also acts as guardian as last resort for some people with intellectual disability. In the last financial year OPA was appointed guardian on 1730 occasions, with around 16 per cent of OPA’s new guardianship clients having an intellectual disability (OPA 2011b, pp. 6-7). Nineteen per cent of OPA’s 563 investigations for the Victorian Civil and Administrative Tribunal (VCAT) in the last financial year concerned people with intellectual disability (OPA 2011b, p. 11). And during the same period 29 per cent of OPA’s 476 individual advocacy clients were people with intellectual disability (OPA 2011b, p. 13).

The theme of this Roundtable is ‘services and families working together’, and we all know that in many ways the glue that holds the disability services sector together is the willingness of families and services to work together to improve the wellbeing of people with a disability. We also know that stresses exist that make the relationship at times a fraught and highly pressured one. Service providers operate with less than ideal resources at their disposal and with a workforce that is not as highly trained or professionalised as it might be. Families, meanwhile, have an emotional investment in the wellbeing of individuals that can never be replicated by a service provider, no matter how empathetic or engaged the service provider might be. Families are the carers of the very great majority of people with a disability, and in those situations where they are no longer providing the primary care, they usually have the knowledge and experience that comes with having provided that care for their family member for longer than anybody else.

At times these tensions reach breaking point. OPA’s Advocate Guardian program becomes involved when there is a failure in what are unsatisfactorily known as ‘informal’ care arrangements. This can occur when there is no family involvement with the person, when family members can’t work together in the interests of the person, or where families and service providers are unable to work together.

There are a number of systemic reform initiatives that are underway in Victoria that engage the interconnecting roles of families and service providers. I want to look at three of these in this paper, which cover the following interrelated areas: the justice system, guardianship laws and supported decision making.

There are a number of other policy developments relevant to people with intellectual disability and their families that I won’t discuss here. These include, for instance, the impact of the continued roll out of Individual Support Packages. On this point, I just note here that a recent report by the Victorian Auditor-General (2011, p. x), while broadly supportive, contained a number of recommendations concerning, for instance, the need for greater equity in Individual Support Package allocation and better crisis support.

The Justice System

There is currently an inquiry being conducted by the Victorian Parliament’s Law Reform Committee on ‘Access to and Interaction with the Justice System by People with an Intellectual Disability and their Families and Carers’. A similar inquiry is going on in New South Wales, with that state’s Law Reform Commission conducting an inquiry into ‘People with cognitive and mental health impairments in the criminal justice system’.
The establishment of the Victorian parliamentary inquiry was, to some extent, a response of the new Baillieu government to the public release by OPA of a report on disability and violence at the start of 2011. That report (Dillon 2010) documented 86 cases of violence suffered by OPA clients in the Advocate Guardian program, and its public release made front page news (McKenzie 2011). Among the many alarming points made in the report was the observation that only one of the 32 disclosures of sexual assault had resulted in a perpetrator being imprisoned (Dillon 2010, p. 15). The government responded by announcing that it would seek ‘the support of the parliament for a reference to the Law Reform Committee to undertake an inquiry into how people with a disability can get better access to justice’ (Wooldridge 2011).

The original terms of reference for the Law Reform Committee (2011) required the Committee to conduct an ‘Inquiry into access to and interaction with the justice system by people with an intellectual disability and their families and carers’. At the end of June a new paragraph was added to the terms of reference which asked the Committee to apply its findings ‘to people with a disability other than an intellectual disability, for example those with an acquired brain injury or neurological condition leading to cognitive disability’.

There are a couple of important points to note about the terms of reference. First, the Committee is investigating not just situations of ‘violence’ but the broader topic of the ‘justice system’. Note also that this reference is not to the ‘criminal justice system’, which suggests that the Committee is interested in access to justice matters in the civil realm. It is also worth mentioning that the Committee is looking not only at perpetrators and victims, but also at families and carers.

OPA (2011c) has now made a substantial submission to this inquiry and given oral evidence. Key among our 22 recommendations we are seeking the following:

- Better support for people with disabilities to bring claims through the criminal justice system (we have called for a witness support program to be established for people with disabilities)
- Better emergency responses to disclosures or suspicions of violence (including provision of alternative accommodation)
- Better preventive measures (including more risk conscious accommodation decisions and better education strategies).

Other improvements OPA would like to see include the following:

- Better disability assessments of prison populations, and provision of appropriate services. Currently the number of prisoners with intellectual disability (see Holland et al 2007, pp. 17, 26) is significantly underestimated because of the lack of active screening. A trial screening process is reportedly being developed in Victoria.
- Consideration of the impact of any abolition of suspended sentences on people with disabilities and their families.
- Consideration of the efficacy of intervention orders, especially when used in relation to co-habitants.

We would also like to pose the question: should the government be looking to introduce a ‘failure to protect’ crime, where a person with profound disabilities is harmed and where obvious warning signals or dangers were ignored by someone in a position of responsibility? I will be interested to hear people's thoughts about this. The final report of the Committee is due in March 2012.

The Review of Guardianship

Victoria’s guardianship legislation was enacted in 1986 and its enactment was groundbreaking for a number of reasons, most particularly for its use of an informal tribunal to make decisions concerning the appointment of administrators and guardians. Victoria’s guardianship laws are currently being reviewed by the Victorian Law Reform Commission (VLRC).

There have been a number of significant changes since 1986 that have made the review of Victoria’s guardianship legislation imperative.

The paradigmatic disability which the legislation sought to address was lifelong intellectual disability, yet only 16 per cent of OPA’s new guardianship clients in 2010/11 had an intellectual disability. Most of OPA’s new guardianship clients (2011b, p. 7) have acquired disabilities during their lives, such as dementia (33 per cent), acquired brain injuries (18 per cent) or mental illnesses (17 per cent).

This gives rise to policy questions such as whether substitute decision makers should exercise the so-called ‘substituted judgement’ approach to their decisions, and be constrained to act wherever possible in accordance with a person's pre-incapacity wishes and behaviour. This can
be quite contested terrain, especially when the implementation of such pre-incapacity wishes may lead to harm of some kind (the substituted judgement approach also raises philosophical questions about the extent to which people should be bound by their previous choices). The Victorian Law Reform Commission (2011, pp. 327-330) is considering this matter.

Another trend in the guardianship jurisdiction, which can be depicted as part of the modern risk management approach, concerns the increasing expectation among some in the disability field that formal decision-making authority should exist as a matter of course in relation to people with cognitive impairments. This can be seen as a form of risk transfer (see further the work of David Green, Anne-Maree Sawyer and colleagues (Green 2007, Green and Sawyer 2008, Sawyer 2008, Brett et al 2010). One quite trivial anecdote here from OPA serves to illustrate the modern interplay between guardianship and risk management. One of OPA’s guardianship clients wished to go horse riding, and it was only when the guardian gave her approval that the service provider arranged for this to happen. The risk was with the guardian, not the service provider. (I note here that the decision itself was an ‘everyday care’ one rather than technically the sort of decision a guardian has authority to make.)

At the same time that this is happening, a trend at the policy and legislative level runs in the opposite direction, which is informed as much as anything by international human rights developments. This trend may be described as the push to limit the state’s appointment of substitute decision makers to situations of absolute necessity. The key development here is the adoption in 2006 of the United Nations Convention on the Rights of Persons with Disabilities (signed by Australia in 2007 and ratified by Australia in 2008).

Article 12(2) of the Disabilities Convention holds that ‘... persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’, while Article 12(4) states that: ‘... all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse ... Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, ... apply for the shortest time possible and are subject to regular review ...’

Nor should this be seen as mere aspiration. While the enforceability of United Nations treaties in Australia is far from automatic (see, for instance, Chappell, Chesterman and Hill 2009, p. 214), the ratification of a treaty amounts to a legal statement by the country in question that the country considers itself bound by the treaty’s terms, and the consequences of breaching a treaty can be unpredictable. When it comes to state-level policy, the enforceability of ratified international treaties is clearer, with the federal government having in its armoury the constitutional ability to broaden its policy reach through use of the external affairs power.

In essence the point here is that state governments increasingly consider themselves bound to implement the spirit and letter of international treaties such as the Disabilities Convention.

There is an argument, which I won’t engage further here, that guardianship itself is inconsistent with the Convention. I will just make the point here that Australia ratified the Convention on the understanding that the Convention does allow for guardianship orders to be made, and indeed Australia made a declaratory statement to this effect.

Suffice it to say that this trend away from state-appointed substitute decision making is influencing the reform of guardianship laws throughout the world. Here in Victoria there is a considerable amount of energy being put in the guardianship review process into looking at alternatives to substitute decision making, which I’ll examine in the next section on supported decision making.

The Victorian Law Reform Commission is examining a number of important reform proposals that I won’t discuss in detail here. One of the more significant reform proposals is that OPA acquire broader investigation powers in relation to people with disabilities who are subject to abuse, exploitation or neglect (see VLRC 2011, pp. 375-6). Other important areas for reform include processes at VCAT, medical treatment arrangements where a person cannot consent to treatment, and the interrelationship between guardianship and other laws, including mental health and disability legislation (see VLRC 2011).

One important proposal in relation to this Roundtable brings two of the conflicting trends I have discussed to a head, namely:

- the increasing desire, particularly among service providers, for formal decision-making authority to exist in relation to people with cognitive impairments, and
• the move away from state-appointed substitute
decision making (which is informed by
international human rights developments).

The proposal that pits these two trends against
each other concerns so-called ‘anticipatory’ orders
and is of particular relevance to people with
intellectual disability and their families and
carers. I’ll discuss this proposal in some detail
here.

The vast majority of people with intellectual
disability, and indeed most people with any form
of cognitive impairment, do not have formal
decision makers appointed by, or for, them. They
do not have guardians or administrators, and have
not appointed representatives under enduring
powers of attorney. ‘Informal’ arrangements (and
again I point out the unsatisfactory nature of this
term) are the norm.

Long-term carers of adults with lifelong disabilities
are often surprised to learn that they have limited
legal status with regard to the person in their
care. This is particularly the case for parents who
are carers of their adult children. The reason why
such carers do not have formal decision-making
authority is somewhat circuitous, but can be
explained like this. One of the central criteria for
the appointment of a guardian or administrator
is that the proposed represented person is in
need of such an arrangement (Guardianship and
Administration Act 1986, sections 22(1)(c), 46(1)(a)
(iii)). When a satisfactory informal arrangement
is in place, VCAT will not disrupt it and make
a guardianship or administration order. So,
somewhat circuitously, the reason the parent
won’t be appointed guardian is because the parent
is already there providing support. There is no
need for an order.

Unsurprisingly, many lifelong carers are unhappy
about this, and the Victorian Law Reform
Commission (2011, pp. 202-4) is considering
whether a new form of order, a so-called ‘anticipatory’ order, might be put in place here.
The idea is that a person could be appointed as the
guardian or administrator when someone they
care for is likely at some future point to be in need
of such an order.

OPA has several concerns about this possible
development.

OPA is concerned about guardians and
administrators being appointed on the basis of
possible or likely future need, simply because of
the unintended consequences that might result.
The considerable emphasis now being placed on
ensuring that the least restrictive guardianship
arrangements are in place will likely jeopardize
if VCAT is empowered to make anticipatory
orders. The impulse in the making of such orders
will be to be overly protective. Indeed OPA has
pointed out that this reform would run counter to
the trend, driven by international human rights
developments, to reduce state-appointed substitute
decision-making arrangements to situations of
absolute necessity.

In addition, the creation of such orders will also
inevitably accelerate and normalise the growing
trend among service providers to expect that
substitute decision-making arrangements are, or
will be put, in place for people with cognitive
impairments. This will lead to more and more
guardianship applications, which will not
necessarily be of benefit to people with cognitive
impairments.

Finally, OPA is of the view that the making of an
anticipatory order will not actually give life-long
 carers quite the power that many suspect it might.
It would give the guardian an elevated ability to
make key life decisions in relation to the person
in their care, but I point out that people, including
carers, can now make guardianship applications if
key life decisions are being made to the detriment
of the person in their care.

Having said all that, OPA is very sympathetic
to the claims of life-long carers, who are almost
uniformly known to be undervalued and
underappreciated by the disability services system,
and indeed by society more generally. OPA has
suggested some other changes to the law that
might be made. OPA, for instance, has proposed
that life-long carers be afforded an elevated ability
to receive information about the person in their
care (overcoming privacy restrictions). We have
also argued that life-long carers should be able
to assume a legally recognised advocacy role in
relation to people in their care.

Again, I’ll be interested in people’s thoughts about
this issue.

**Supported Decision-making**

The final area I wish to address is developments
in the supported decision-making field. In some
ways, as Barbara Carter has pointed out (2009,
p. 3), supported decision making is something
everyone does to some extent. Almost no-one
makes all their decisions in isolation from the
advice and support of anybody else.
But over the last two decades the term ‘supported decision making’ has come to refer to the group of practices whereby people with cognitive impairments are assisted to make or implement decisions about their own lives (Carter 2009, p. 4). The unarguable underwriting principle here is that people with cognitive disabilities generally have the capacity to play greater decision-making roles in their lives than they currently exercise.

The most significant source of authority for the increasing utilisation of supported decision making is the *Convention on the Rights of Persons with Disabilities*. While the term ‘supported decision making’ does not appear in the Convention, there is agreement that the Convention requires substitute decision making to be minimised wherever possible.

As the United Nations ‘Enable’ (2011) website points out:

‘The Convention recognizes that some persons with disabilities require assistance to exercise [legal] capacity, so States must do what they can to support those individuals and introduce safeguards against abuse of that support. Support could take the form of one trusted person or a network of people; it might be necessary occasionally or all the time … Supported decision-making can take many forms.’

In other words, whenever a person can be assisted either to make, or have a central role in, decisions that affect them, then that should be preferred to substitute decision-making.

Supported decision-making initiatives all seek to improve the extent to which people with disabilities take part in the making of decisions that affect them. One of the questions that faces supported decision-making advocates concerns the extent to which initiatives in this field require legislative and policy changes in order to be implemented.

There are a range of initiatives able to be undertaken within existing legal and policy settings. For instance, Jo Watson and Rhonda Joseph at Scope have done considerable work at the service delivery level to show how supported decision-making principles can be used to improve the involvement of people with even the most profound disabilities in decisions that affect them. At the same time the Department of Human Services has constructed a guide to help services implement the principles of supported decision making, which I am advised should be available very shortly.

Work is also being conducted at the policy and legislative level to create supported decision-making alternatives to existing substitute decision-making options.

Substitute decision-making arrangements confer on somebody the authority to make decisions about another person. Guardians and administrators are examples of substitute decision makers. They are appointed by VCAT to act in a substitute role. Another example of substitute decision making occurs when an enduring power of attorney enables a personally-appointed representative to stand in the shoes of a person who is deemed no longer to have the capacity to make his or her own decisions.

The line separating substitute decision making from supported decision making is not as clear as the theory might have it. For instance, guardians and administrators are required, in exercising their substitute decision-making power, to take ‘into account, as far as possible, the wishes of the represented person’ (*Guardianship and Administration Act 1986*, ss. 28(2)(e), 49(2)(b)). And OPA’s Advocate Guardians certainly work within a culture that is very receptive to the underwriting principles and impulses that are driving supported decision-making developments. But the point also needs to be made that substitute decision makers do have ultimate authority to override the wishes of the people for whom they have been appointed.

A number of developments are going on that seek to utilise supported decision making as an alternative to guardianship.

For instance, the South Australian Office of the Public Advocate is involved in a pilot project that is testing the extent to which supported decision-making arrangements can obviate the need for guardianship orders.

Meanwhile Michelle Browning (2010), who works at the New South Wales Office of the Public Guardian, undertook a Churchill Fellowship in 2010 and wrote a report on the transferability of certain overseas supported decision-making developments into Australian (particularly New South Wales) law and practice.

I want here to focus, though, on recent developments in the review of Victoria’s guardianship laws, with the Victorian Law Reform Commission signalling that legislative change in this area is, or should be, on the horizon.
In its 2011 Consultation Paper the Commission (VLRC 2011, pp. 129-32) suggested giving legislative recognition to two possible supported decision-making innovations.

The first proposal is that ‘supported decision-making agreements’ could be entered into by people who might not be deemed to have sufficient capacity to enter other legal arrangements (such as enduring powers of attorney). These agreements would enable one or more supporters to access private information about the person being supported and to advise others of decisions that have been made. But these supporters would not be decision makers. The Commission (p. 130) compares such a proposed supporter to the Centrelink ‘correspondence nominee’ a person might have.

The Commission (p.130) has also proposed creating ‘co-decision-making agreements’, in which people could nominate another person as someone with whom they will make joint decisions (see also Chesterman 2010, pp. 11-12). These agreements would be particularly useful, the Commission envisages, for people with fluctuating or declining capacity, who would not be ceding all power to a substitute decision maker. Decision-making responsibility would be shared.

In addition to these two new forms of personal appointment, the Commission (p. 131) has proposed that VCAT be able to make orders to the same effect; namely ‘supported decision-making orders’ and ‘co-decision-making orders’.

While the Commission (p. 132, 379), rightly in OPA’s view, does not believe OPA should have a role as a supported decision-maker or co-decision maker, OPA might have responsibility for establishing a new volunteer program that would encourage members of the public to take on these new supported decision-making roles.

It remains to be seen whether the Commission will include these proposals in its final recommendations, which are due at the end of December 2011. There are two main arguments against their inclusion. One is the simple fact that they would add complexity to an already inadequately understood jurisdiction. The other is that supported decision-making arrangements, particularly in the financial realm, might too easily enable the abuse of people with disabilities (see Chesterman 2010, pp. 8, 10). OPA, for the record, hopes that the proposals are included in the Commission’s final recommendations, and indeed that they are introduced into new guardianship legislation in due course.

Conclusion

This paper has considered possible policy changes in three areas that would, in OPA’s view, lead to improvements in the lives of people with intellectual disability. I look forward to discussing these and other developments with participants at this Roundtable.

References


Victorian Auditor-General, 2011. Individualised Funding for Disability Services (Melbourne).
Participation Rights, Family-Decision-making & Service Access: A Role for Law?

Terry Carney, University of Sydney

The [Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act 2008 Ontario] is intended to shift Ontario’s developmental services sector away from institutionalized care and towards a system of services and supports that will enable people with intellectual disabilities to exercise more independence, have greater decision-making power over their day-to-day lives, and ultimately live as full citizens in communities of their choosing. ... This report ... asserts that there are significant limitations to the new legislation .... Two of these limitations are: the absence in the legislation of rights for people with intellectual disabilities when they receive developmental services and supports; and the lack of robust mechanisms to enforce such rights (Joffe, 2010: 5).

Introduction.

Ontario is not alone in querying the part able to be played by law in achieving social justice objectives, such as securing rights to human services or health care (Harrington & Stuttaford, 2010). The role of law in the interplay between individual autonomy, family decision-making, guardianship and access to services for people with intellectual disadvantage is both challenging and changing (Carney & Keyzer, 2007a). It is ‘challenging’ on various fronts, including: (i) because contemporary visions of supported community living may not be a good fit with currently more paternalistic substitute-decision-making laws in some countries (Šiška & Beadle-Brown, 2011); (ii) because even the latest service-provision and funding arrangements fall short of truly honouring respect for individual choice; (iii) because family involvement can be fraught; and, finally (iv) because policy and practice often diverge (Dunn, Clare, & Holland, 2010).

The role of law in this field is ‘changing’ for a host of reasons, including: (i) because of pressures generated by shifts towards equality and supported decision-making at the international level in treaties such as the Convention on the Rights of Persons with Disabilities (CRPD, 2006); (ii) because of impacts of changing patterns of family composition on the capacity to maintain past preferences for reliance on informal support/care; (iii) because of changing fashions about models of adjudication and regulation; and, finally, (iv) because neoliberal trends in government provision of services can both diminish the stock of public goods available to people with disability and attenuate the visibility and accountability of issues of distributional justice. While some of those changes are rather miniscule in their impact, as in fostering transition planning through easing social security treatment of disability trusts (Carney & Keyzer, 2007b), others—such as Australia’s proposed national disability scheme (Dyson & Canobi, 2011; Productivity Commission, 2011a, , 2011b), or principles of supported decision-making—are potentially very powerful.

This exploratory paper canvasses some of the issues for Australia around giving substance to the CRPD’s favouring of supported decision-making (Part B), and the way this might impact on service access and realisation of socio-economic rights to services (Part C). It is suggested that the first can be portrayed as an issue of use of the law as advocacy or ‘brokerage’ for individuals seeking to realise the right to participation (a civil right), while the second can be characterised as an issue about using the law either as a ‘ticket to service’ or to achieve systemic accountability (sounding in the arena of socio-economic rights). As argued in the conclusion, law makes a minor, if necessary, contribution in both areas.

Supported Decision-making?

Due to the influence of the CRPD and advances in practice, replacement of paternalistic substitute-decision-making by the autonomy and dignity-enhancing concept of supported decision-making is now a priority. However this may be easier said than done at the legal or practical level, and it poses greater operational challenges for the intellectual disability sector than for other disability groups (such as dementia or mental illness).

What is supported decision-making?

One of the areas where Victoria is leading Australia is in rethinking adult guardianship laws to incorporate ideas of ‘supported decision-making’
Unlike traditional guardianship, the idea is that the person retains their legal powers of decision, but a third party is authorised by law to do such things as provide assistance, or access and share their personal information.

Such reform proposals represent a newer trend towards giving legislative recognition to processes that may already occur on an informal basis. Individuals with a disability depend upon social networks of family members, friends and others to assist them to make decisions at different times and to varying degrees; as Bigby writes, ‘people with disabilities are part of complex family systems which play multiple, diverse and changing functions in the lives of all family members’ (Bigby, 2011: 2), forming ‘circles of support’ (Watson, 2011). In fact, it is often argued that supported decision-making ‘simply recognizes the way in which most adults function in their everyday lives (Gordon, 2000: 65), via processes of interdependent decision-making (Reindal, 1999), drawing on the opinions, advice and skills of a range of people within their social networks, professionals and experts, as needed.

Supported decision-making encompasses a range of processes to support individuals to exercise their legal capacity, including:

- effective communication, including in the provision of information and advice to a person and through ensuring that a person is able to communicate their decisions to others;
- spending time to determine a person’s preferences and wishes;
- informal relationships of support between a person and members of their social networks;
- agreements or appointments to indicate that a relationship of support exists; and
- statutory relationships of support—whether through private or court/tribunal appointment.

Many such processes do not require legislative provision for their implementation but are rather contingent on the policies and practices of services, agencies and institutions that interact with people with intellectual disabilities and their social networks, as well as the organic development of relationships of trust and interdependence that develop between people.

Legislative categories of supported decision-making are intended to ensure that people with disabilities receive sufficient support in appropriate cases where adult guardianship is considered too restrictive, whilst simultaneously avoiding the unnecessary use of full guardianship by providing a viable less-restrictive but structured alternative (VLRC, 2011: para 7.55). Such formalisation of supportive relationships should ideally also provide certainty, in particular in dealings with third parties, as regards the legal capacity of people with disabilities and the legitimate role to be played by those providing them with support (VLRC, 2011: para 7.57). Various legal mechanisms which fall under the supported decision-making banner have been in place in several European and Canadian jurisdictions for some time now, using an array of terms including ‘assistants’, ‘support people’ and ‘advocates’ (Gordon, 2000: 63). ‘Supported decision-making’ has only more recently, however, gained currency as an umbrella term in disability-related law and policy reform debates and initiatives.

Victoria pioneered the previous wave of reform in the 1980s, introducing accessible, partial and time-limited guardianship in place of the former costly and inaccessible plenary guardianship (Carney, 1989). These reforms drew on a model from Alberta Canada, under its then (but recently since replaced) Dependent Adults Act 1978; however these reforms still retained a paternalistic cast (applied a ‘best interests’ principle) and provided for substitute decision-making. Guided by the ‘equality’ principle of Article 12(2) of the Convention on the Rights of Persons with Disabilities,\textsuperscript{iv} the Victorian Law Reform Commission’s review of guardianship law (VLRC, 2011) has endorsed shifting the emphasis as far as possible towards ‘supported’ decision-making. Some of the meaning and practical implementation of this remains a work in progress internationally (Carney, 2012 forthcoming), though light may be shed by the small two year trial of supported decision-making in South Australia (OPA[SA], 2011).

\textsuperscript{iii} For an overview of the stepped options comprising supported decisionmaking, see (Office of the Public Advocate South Australia, 2011: 11-12)

\textsuperscript{iv} Article 12(2) provides that ‘States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’ [emphasis added]. Article 12(4) however stipulates that ‘all measures that relate to the exercise of legal capacity’ shall provide for ‘appropriate and effective safeguards to prevent abuse in accordance with international human rights law’, before going on to expressly refer to ‘respect[ing] the rights will and preferences of the person’, freedom from ‘conflict of interest and undue influence,’ and being ‘proportional and tailored to the person’s circumstances, applying for the shortest time possible, and subject to regular review…. .
Taking its lead from Canadian models in various provinces (Burningham, 2009) such as Alberta’s new *Adult Guardianship and Trusteeship Act* 2008 based on the Ady Report (Alberta, 2007), provision is proposed to be made in Victoria for two additional legal options apart from guardianship: namely supported decision-making and co-decision-making. Both of these options were originally envisaged as being able to be invoked as private-planning agreements (enduring powers) prior to loss of capacity, as well as constituting additions to the public sector legal toolkit at the disposal of the guardianship division of ‘VCAT’—the Victorian Civil and Administrative Tribunal (VLRC, 2011: para 7.87). The latter avenue, however, arguably offers the greater protection of the delicate balance of competing considerations at stake.

Alternatives to formal appointments of supporters—which reveal the diverse roles (if any) the law may play—also give food for thought. *The Vulnerable Persons Living with a Mental Disability Act* of Manitoba, for example, which provides for appointments of substitute decision-makers and a framework for the delivery and oversight of support services, incorporates the concept of supported decision-making by: (1) defining this concept with reference to assistance provided by a person’s ‘support network’; and (2) requiring that supported decision-making be respected as a means to enhance the person’s self-determination. Supported decision-making is an informal arrangement promoted by the Act as an alternative to be preferred to substitute decision-making, and support networks are noted as one among several parties that may be involved in and informed about processes under the Act. Research on the implementation of the Act reveals the complexity of operationalising informal support networks and the difficulties involved in realising the capacity-respecting goals of the Act, without careful attention to the necessary administrative and policy machinery (Lutfiyya, Updike, Schwartz, & Mactavish, 2007).

Facilitating the use of private supported decision-making avenues in tandem with VCAT ordered appointments as an alternative to the deeply-entrenched practice of making guardianship orders would present a challenge, particularly in the intellectual disability sector, where capacity is usually assumed to be lacking from the outset. Australia’s public guardianship options are certainly much richer than in Alberta and most of North America (where well funded government default guardianship or offices like the Office of Public Advocate, ‘OPA’ are rare), so they are arguably better placed to craft support arrangements more reflective of the collectivist ‘circles of support’ decision-making more apt to the sector (Watson, 2011). In addition to the practical issue of identifying and encouraging the growth of support networks—especially for those people who are socially isolated (Lutfiyya et al, 2007: 141)—part of the challenge will be developing a culture that views (formal) supported decision-making as a viable alternative to guardianship in appropriate cases.

**Supported decision-making may have unintended effects?**

As argued in more detail elsewhere (Carney, 2012 forthcoming), for the most socially isolated and vulnerable constituencies, even these 21st century models of supported decision-making, including the more radical ones, may not be as different from their predecessors as is sometimes presumed. There is also the risk that promoting supported decision-making may conflict with a person’s right to make their own decisions by effectively enforcing this model on some individuals who do not want assistance in making decisions (Lutfiyya, Updike, Schwartz, & Mactavish, 2007: 50).

Rather than serve the intended aims of encouraging private planning over the need to approach VCAT for an order (in the interests of being cheaper and offering more scope to reflect individual values and preferences), and rather than reducing the proportion of people under formal guardianship (in the interests of being the least restrictive

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V The Alberta Act, operative from October 2009, now provides for nomination of supported decisionmaking authorisations (s 4), and court-appointed co-decisionmakers (s 13) in addition to guardianship or trusteeship machinery (Alberta, 2009). Alberta law shares some features of laws in Saskatchewan (Supreme court co-decisionmaker orders), Manitoba and the Yukon, or the representation agreements in British Columbia (Burningham, 2009; VLRC, 2011: paras 7.33-7.35).


VII A substitute decisionmaker should not be appointed if the person is capable of attending to their personal care or managing their property (Alberta, 2009; ss 53(1), 88(1)).

VIII In a paper commissioned by the Ontario Law Reform Commission, Bach and Kerzner argue for a ‘will-based’ approach to competence, distinguishing between legally independent, supported-decisionmaking (where others assist realisation of the will, identity and values of the person), and ‘facilitated-decisionmaking’—a temporary status for isolated people to whom the state owes a duty to find the means of realisation of their will (2010). However the practical realisation of this is not without its problems (Bartlett, 2011).
orders)—these new options may simply expand the reach of guardianship. Despite the advantages of contemporary understandings of disability as contextual and fluctuating, insofar as disability ‘is seen as fluid and rooted in the social context’, individuals may be subjected to continuous monitoring regarding their state of functioning and their access to benefits and services (Carey, 2009: 216). Such unintended consequences are common in other areas of policy (such as juvenile justice ‘diversion’), where ‘net widening’ is a well documented risk.

While of some concern, such an outcome may not necessarily bring the undoing of such reforms, since there are costs and benefits to weigh up:

The size of any such unintended effect of that character is of course currently unknown; and its aggregate policy position is uncertain as well (in that the increased intrusiveness of any net widening may be off-set by the greater case ‘monitoring’ or support able to be brought to bear). Likewise the unintended effects of allowing holders of the new instruments (or those dealing with them) to appear to have the very decision-making powers which the law has expressly withheld from them; while education, registration and monitoring may mitigate this risk,… it cannot possibly avoid the honest misunderstandings about ‘what power is what’ (Carney, 2012 forthcoming: ms 15-16).

The qualification in this quote regarding the mitigating effects of education and other monitoring is in recognition that the Commission has proposed a number of such measures to complement the reforms (see VLRC, 2011: paras 7.113-7.116).

My point here is simply that they may not be enough.

**Just de facto guardianship?**

The second issue touched on by the quote is in some ways more profound: that the reformed law may in practice be understood by stakeholders as little different from its predecessor. It has previously been queried whether the ‘brokerage role of a modern decisional assistant’ under the supported decision-making model is ‘actually just the functional equivalent to that of a traditional guardian or administrator discharging their statutory duty to first act as an advocate (or the ‘eyes, ears and voice’) for the person they represent?’ (Carney, 2012 forthcoming: ms 17).

For both users (for whom the two services may be indistinguishable) and governments (facing similar costs in monitoring and educating citizens who make themselves available for these roles, or in recruiting ‘community guardians/supporters’ for those lacking family), the distinction between old guardianship and new supported decision-making may be small; both are essentially ‘publicly-funded, arranged and facilitated’ (ibid).

That said, a shift to supported decision-making is highly to be commended on the basis of its symbolic significance:

> It can be argued that at the very least a shift towards supported decision-making sends two important symbolic messages regarding: (i) rejection of avoidable paternalism; and (ii) the repositioning the state as an adjunct to (or facilitator of) civil society (ibid, ms 18).

By the first is meant the intrinsic value of the ‘dignity’ interest associated with the self-respect associated with not being ‘obliged to’, or ‘reliant on’, third-parties (further, Salzman, 2010: 168-70), while the second takes on board capacity-building and the ‘capabilities’ views of social justice (see for instance: Sen, 2009). Avoidance of charitable overtones and positioning within a capacity-respecting narrative are valuable achievements in their own right.

Disability related law, including guardianship law, may be criticised for constructing a negative ontology of disability (Campbell, 2009), requiring applicants for guardianship or services to be presented as a ‘worst case’ (OPA\[SA\], 2010: para 44). Shifting to a supported decision-making model presents an opportunity to re-imagine the disabled legal subject in alternative ways, although the extent to which this is possible where supported decision-making is positioned within guardianship regimes and overshadowed by the substitute decision-making model may be called into question. I would argue that reforms such as those proposed by the VLRC nonetheless represent progress towards the notion of legal capacity enjoyed by people with disabilities ‘on an equal basis with others in all aspects of life’ proffered by the CRPD.ix

There is however also a related practical issue to be mindful of in designing supported decision-making, and that is how to educate the public

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ix For a detailed discussion of the debates in the construction of the concept of ‘legal capacity’ in the Convention, see (Dhanda, 2007)
about the total lack of any decisional power which these appointments convey to their holders. While unnecessarily compounded overseas when words like ‘co-decision-making’ are used to (mis) describe such appointments, even well-informed professionals, service providers and businesses with whom holders of these powers will have dealings, are likely to genuinely assume that decisional powers are conferred, irrespective of the name attached to such arrangements. Just as many bank officials and others still fail to appreciate the effect of or even recognise enduring powers of attorney a decade or more after their introduction, some additional confusion and misuse seems unavoidable.

Given educative measures to raise awareness amongst those who deal with people with an intellectual disability that control over decision-making resides with the supported person, supported decision-making should, however, ideally prevent informal substitute decision-making from occurring. One theme that has emerged from the South Australian trial of non-statutory supported decision-making agreements is that informal decision-making support arrangements can lead to others making decisions for a person with a disability: some people seek an agreement to prevent family and friends from taking over their life.

The short point is that social reforms inevitably bring both benefits and risks, so a variety of options need to be weighted up. Eilionoir Flynn’s (2010) analysis of Ireland’s Citizens Information Act 2007 (largely implemented from January 2011), for a Personal Advocacy Service to assist disabled people to access social services and offer ‘support or training... to promote the best interest of his or her health, welfare and well being’ (ibid, 26), offers an instructive review of the range of informal and formal alternatives, and their pitfalls. Drawing on Stone’s metaphors of ‘standing in front of’ (representing), standing beside (‘shared partnership’) and standing behind someone with a disability (‘self-advocacy’), the latter might be seen as the ideal, with a partnership as the minimally acceptable stance to aim for.

Some of the implications regarding service access and the law are tackled in the next section.

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**Services, Families and Grievances.**

Models of service provision for people with disabilities worldwide are in the course of shifting from state-funding of organisational providers to one of provision of individual ‘packages’ of resourcing under the control of the person with the disability, often known as ‘personal budgets’ (led locally by Western Australia: Fisher et al., 2010). Victoria too is moving in this direction, but still mainly operates a ‘purchaser-provider’ model where the Disability Services Department funds ‘registered’ service providers and seeks to hold them accountable for the both the quality and the philosophical orientation (autonomy-enhancing character) of services. As with the critique of Ontario, such models are problematic without genuine empowerment of intellectually disabled people as autonomous consumers.

**Benefits and challenges associated with flexible funding**

Flexible funding is designed to maximise personal choice and autonomy, but there are difficulties to be overcome with the model for groups such as people with intellectual disability.

As Laragy and Ottman’s study (2010) of flexible funding in England, Scotland, Sweden and Australia observed:

In each country studied, support for flexible funding is growing, but there are also dissenting voices highlighting its limitations. Questions are asked about programmes that are designed to meet the needs of people with a physical disability at the expense of those with learning difficulties; whether the most vulnerable will be left without support; whether a market economy will ignore the marginalised who are unlikely to provide a profit; whether people will be left isolated and vulnerable at home if there is no case manager to notice inadequate resources or to advocate on their behalf; and whether people living independently may become more isolated and less socially engaged (ibid, 131).

While some gains in participation were generally obtained under this model, a great deal is shown to depend on the overall level of resourcing and the degree of recognition of the complexity of

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x The trial involves the person nominating one more people they know to act as a supporter and the use of ‘monitors’ to help with the process, assist with problems and assume a safeguard monitoring role: Office of the Public Advocate, ‘Supported Decision Making Project: August 2011 Update’ http://www.opa.sa.gov.au/cgi-bin/wf.pl?pid at 8.

xi Office of the Public Advocate, 2011.


xiii Providers also face challenges, such as in maintaining the contracts needed to recruit and retain quality staff (Baxter, Wilberforce, & Glendinning, 2011).
variables in play in such decision-making, among other factors (Laragy & Ottmann, 2011).

For example, in several countries, lack of resourcing appears to have cruelled development of adequate personalised accommodation options for aging of people with intellectual disabilities, as family carers become unable to continue (Bigby, 2010)—something that the large injection of funds associated with any Australian national disability scheme may ultimately be able to rectify at least for issues such as housing. Marshalling less tangible resources (civil society and personal support) and accountability issues also loom large, however. Staff associated with individualised housing options for instance have been found to give greater priority to promotion of individual participation rights, while care needs are the ones emphasised by staff in congregate housing settings (McConkey & Collins, 2010); though of course the magnitudes of any such contributions are plainly not immutable, but may be responsive to training and other capacity-building interventions. Fostering the development and skills of social networks of people with severe intellectual disabilities (Johnson, Douglas, Bigby, & Iacono, 2010) is another obviously crucial element of any capacity building approach. This joins the host of other civil society ‘spaces’ which may potentially be rendered more receptive for people with intellectual disabilities (such as developing inclusive cultural spaces: Hall, 2010). Such initiatives would desirably expand our social policy focus beyond the more familiar benefits (and risks associated with breakdown) of initiatives designed to foster engagement in the world of work (Banks, Jahoda, Dagnan, Kemp, & Williams, 2010).

Of course all of these can be conceptualised as ways of securing ‘social rights of citizenship’, as famously envisioned by TH Marshall (Carney, 2012 forthcoming; Marshall, 1963); or, in more modern guise, as examples of initiatives which subscribe to the (slightly amorphous) rights-based-approaches to social policy for people with intellectual disabilities. Securing such positive socio-economic or social rights (the right ‘to’ something) is however notoriously difficult to realise through law, which traditionally only guards against infringements of civil rights (the right to be protected ‘from’ something). So do current or proposed Victorian laws put a more positive gloss on it?

**Leveraging support through supported decision-making?**

Supported decision-making is one possible avenue. In many ways, the quality of life experienced by people with an intellectual disability hinges on maximising their own independent capacities and autonomy of action, while also providing the ‘brokerage’ assistance to enable mobilisation of public and private resources in accordance with their values and preferences.

Of course that ‘agency’ is able to be facilitated only to the extent that the service sector and civil society actually offer resources able to be mobilised (Carney, 2012 forthcoming; Šiška & Beadle-Brown, 2011: 129, 131). On the other hand, the need for such brokerage is undoubtedly growing due to governance changes, such as the otherwise entirely commendable shift towards ‘personalised budgets’ in place of standardised service provision (see for example: Fisher et al., 2010: 7-13). In short, the space for agency to be realised is expanding, and the complexity of the choices to be made within that space is also increasing.

This is certainly one area where supported decision-making can offer some tangible assistance, such as by clothing decisional assistants with the legal authority to access and receive information otherwise privy only to the intellectually disadvantaged person due to privacy protections, and by enabling the assistant to ‘join’ the person in providing information to government or other outside agencies, and generally by assisting in amplifying the ‘voice’ (and lobbying power) of the individual with a disability. These are not entirely radical ideas of course. In social security, provisions have existed in Australia for a number of years which permit a person to be appointed as a ‘correspondence nominee’ in respect of a pensioner or beneficiary’s dealings with Centrelink.**xiv**

How far this advances the aspirations of the CRPD or a ‘human-rights-based’ approach to intellectual disability remains somewhat moot, however. Many of these new capacities were previously provided *informally* (indeed ‘extra-legally’) by family or other close relatives of intellectually disabled people. With changing demographics and work expectations, the embrace of risk-aversive practices of utilities (like banks and service providers), and greater recognition of the privacy interests of consumers—such ‘muddling
through’ by informal carers is no longer so prevalent. Might this be a case of taking one small step forward, offset by a half step backwards in terms of reduced capacities of civil society? And, if so, what other leverage might the law bring to bear?

What Else Can Law Contribute To Realisation of Social Rights?

Law has a chequered history in leveraging access to resources, but tribunals can legitimately engage allocative decisions (Richardson & Genn, [2007]) and disability is a field where law has long since been deployed in various creative ways to provide leverage or resolve more complex grievances such as case planning (Carney, 2003).

With the enactment of the Victorian Disability Act 2006, a new tripartite model of accountability and grievance resolution xv replaced the—perhaps underestimated—option for recommendatory review of service plans by an Intellectual Disability Services Panel (Bigby & Tait, 2004; Carney & Akers, 1991). Under the new scheme, the Disability Services Commissioner was introduced, with responsibility for handling a diverse ‘complaints-based’ model of grievance resolution and maintenance of service standards xvii. In practice this is achieved through fielding user or family concerns, and by monitoring levels of and methods adopted by registered organisations to encourage complaints as a mode of internal feedback and provision of information relevant to more systemic issues.

The relative merits of this and other models of governance, such as that in Ontario, cannot be taken as a given however. The Victorian model focuses more on resolution of individual grievances than addressing of systemic issues: it is essentially a more flexible ‘soft-law’ variant of more traditional complaints systems, rather than one designed to leverage socio-economic rights to services. A refreshingly high level of complaints to the Commissioner do come from users themselves (23%) and their family, friends etc. While combinations of disabilities are found for ‘just under half’ of such complaints, intellectual disability (at 60%) was the most frequent constituency the subject of reports (Disability Services Commissioner, 2010: 29). Given that workload therefore, the anecdotal concerns about ongoing poor relationships between service providers and intellectually disabled people and their families give pause for reflection about the (in?) effectiveness of the new Victorian system.

Evidence of better approaches is hard to find however. In a paper commissioned from the ARCH Disability Law Centre by the Ontario Law Reform Commission, Joffe (2010) argued that Ontario’s 2008 Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act was flawed, and would not achieve its purpose of promoting greater autonomy for people with intellectual disabilities. The main concern expressed was at the lack of social rights or any effective means of enforcing such positive or socio-economic rights (ibid, 5). The paper therefore argued for a ‘human-rights-based’ approach to enforcement which, among other things, would recognise the agency and consumer rights of people with disabilities, extend the ‘means’ to intellectually disabled people for their full enjoyment, and be based around four principles of: accountability, accessibility, participation and independence (ibid, 60).

Based on its review of legislation in Alberta, British Columbia, New Brunswick, Quebec, Victoria, the UK, California, and Texas (ibid, 61-104), Joffe noted that government oversight and monitoring of service quality was one common element (as in Ontario), highlighted by the ‘robust inspection and inquiry powers’ in Alberta and Victoria’s ability to appoint an administrator should service standards not be met (ibid, 104). As the report observed, ‘[i]nterestingly, all the jurisdictions surveyed employed complaint and/or appeal mechanisms as an important element of their service delivery systems’ (ibid). While Ontario was criticised for its lack of detail about the complaints procedures agencies must establish, British Columbia and California were commended for setting down ‘very detailed requirements’. As the report went on to write ‘[t]his suggests that robust complaint and appeal mechanisms are an important element of enforcement in every developmental services system, including those in which government oversight and monitoring are emphasized’ (ibid, 104-105).

xv Under the Disability Act 2006 the former Intellectual Disability Services Panel (which had recommendatory powers of ‘merits’ review) was replaced by three new bodies: a Disability Services Commissioner, a Senior Practitioner (stemming from the 2003 VLRC report on imposition of ‘restraints’), and rights of review by the Victorian Civil and Administrative Tribunal (DoHServices, 2006).

xvii Part 3, Div 3; Part 6, Divs 5 & 6.
Turning to its preferred ‘human-rights-based’ approach, the survey commended elements of legislation in California, Victoria and British Columbia, writing that:

California’s Lanterman Act, provides for rights for people with intellectual disabilities in the legislation itself. It also recognizes that people with disabilities should be able to advocate on their own behalves, and permits regional centres and Area Boards to provide self-advocacy training and peer support to those who wish to learn about their rights or make complaints about services. Several of the principles guiding the Australian Disability Rights Commissioner can be linked to a human rights-based approach, including the principles of accessibility, accountability, respect for rights and taking a person-centered approach. In British Columbia [the] Complaints Resolution Policy requires complaint procedures to be accessible and consistent with a person-centered, rights-based approach [and used] the UN Convention on the Rights of the Child as a reference for its policy (ibid, 165).

The desirable feature of self advocacy was identified as encouraged in Quebec, where users committees ‘provide peer support to assist consumers to understand ... and make complaints,’ and also assist in ‘bringing systemic concerns to the attention of a service provider’s Board of Directors’. California’s Area Boards were likewise found to have a role of encouraging and assisting self-advocacy, with some success; while in the UK, service providers were required to make ‘reasonable arrangements to assist people with disabilities to express their views, manage their own care, and support and promote their autonomy, independence and community involvement’ (ibid, 106).

Of course what surveys of this character have not yet done is determine how much substantive effect such optimal approaches might bring. The irony of reading about the commendable features of Victoria in requiring providers to encourage complaints and report outcomes, in light of the Disability Commissioner’s ongoing concerns about high levels of non compliance, cannot be lost on a Victorian disability audience!

Conclusion

From a human rights standpoint the adequacy of this limited contribution of the law is hard to judge. The ‘enjoy[ment of] legal capacity on an equal basis with others in all aspects of life,’ on the part of people with disability, as expressed in Article 12(2) of the CRPD 2006, can be read in several ways.

A narrow reading would translate it as merely the pursuit of formal legal equality by erasing individual incapacities, such as through facilitating the appointment, by those in a position to do so, of a nominated ‘support’ who can help in the realisation of an authentic decision (as in Alberta). A wider reading, however, would read it as an obligation to promote substantive equality, which among other things might require that supported decision-making be available to all, at state expense and under state recruitment where needed, and that support services be subject to greater oversight such as through grievance resolution. Yet another reading would see it as expressing deliberative democracy goals of self-government, partially assisted by legal obligations such as that any advance directive or other statement of a person be presumptively respected by decisionmakers, or support for self-advocacy and consumer participation.

It is not merely a matter of making a choice between such ideal philosophical visions (and others), however. It is a matter of finding the legal, administrative or other policy machinery to bring the chosen vision to fruition. The example from an ethnographic study of decision-making under British competency (guardianship) legislation supposedly guided by the ‘best interests’ of the person, as administratively operationalised in ‘check-list’ weighing of cumulative benefits and disadvantages, is a case in point. In practice this was found to have evolved into a scheme where what the carer judged as the most appropriate decision in light of the carer’s own values and life calculus was substituted for the intended focus on the person with the disability (Dunn, Clare, & Holland, 2010). Plainly this outcome runs counter to autonomy and self-actualisation goals. However it is also open to a more favourable portrayal as a rough and ready reading of democratic values of participatory self-government by people closest to those affected, and the pluralist cross section of values of that community (Carney, 2012 forthcoming: ms 21).

Not only is the current or future role of law somewhat marginal on the evidence canvassed in this paper, then, but even a normative conclusion about what it ideally should contribute may also be rather more debatable than at first assumed.
References


Richardson, G., & Genn, H. ([2007]). Tribunals in Transition: Resolution or adjudication? *Public Law*(Spring), 116-141.


Notes