

PLANNING FOR THE FUTURE: ARRANGEMENTS FOR THE ASSISTANCE OF PEOPLE PLANNING FOR THE FUTURE OF PEOPLE WITH IMPAIRED CAPACITY

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The carers of people with impaired capacity, whether caused by developmental disability, acquired brain injury, chronic mental illness, or conditions such as dementia, frequently want to make plans for a future situation when they are no longer able to care for themselves or their loved ones. In an ageing population,³ demand for such services is rising.⁴

Research indicates that there is a significant unmet need for legal services for these people.⁵ People with impaired capacity and their parents and carers need better access to legal planning and related services; and services that are inexpensive, well-informed,

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³ Australian Government, The Treasury, *Australia's Demographic Challenges* (2004).

⁴ Access Economics, *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia* (2003).

⁵ P Keyzer, T Carney and D Tait, *'I Hope He Dies Before Me': Caring for Ageing Children with Intellectual Disabilities* and *'Against the Odds: Parents with Intellectual Disability* (Sydney: Commonwealth of Australia/University of Technology, 1997). Planning for the future can involve professionals in law, financial services, social work and other disciplines. It can involve formal and informal planning. Our focus here is on formal legal planning for the future, though we do comment on the legal dimensions of informal planning.

independent, reliable and sensitive to their needs.⁶ Meeting the needs of people with impaired capacity is an issue of fundamental human rights.⁷

Lawyers have a responsibility to help to explain and utilise legal planning tools which might improve the future lives of both carers and the people they care for. The first step in analysing their obligations is to identify their potential clients. This paper reviews institutional and administrative arrangements, laws and mechanisms for independent oversight of financial management arrangements for people with impaired capacity, particularly in Queensland. It identifies the people who may have impaired capacity and focuses on the legal needs of their parents and carers (particularly older parents and carers) as part of the broader framework of planning for the future. It identifies and critically analyses the legal tools (public and private) used to assist in future planning, the social dimensions of providing legal planning, and identifies some themes for further reform of the law and its practice in this context. Particular attention is paid to older carers of people with lifelong developmental disability that can result in impaired capacity.

The feature of central interest in this article is the growing number of people with a cognitive disability who are unable to count on the continuation of the informal care and in-kind economic benefits previously provided by their now ageing carers, and for whom explicit, or implicit extra-legal planning proves to be an insufficiently secure replacement.⁸ Our focus will be on addressing the planning needs that this poses, especially assistance in making legal provision to ease the transition which inevitably arises on the death or incapacity of carers. More specifically, we concentrate on those legal tools able to facilitate replacement of the informal roles of that carer, either by providing (or preserving) needed income, assets or services (such as through private trusts, wills, enduring powers of attorney, or pension ‘nominee’ provisions);⁹ and/or by providing needed substitute decision-making authority or oversight of daily living (such as through private enduring powers of personal guardianship, adult guardianship orders, or well chosen trustees). In conducting this review we will be conscious of the normative framework provided by human rights principles.¹⁰

I WHO ARE THE PEOPLE WHO MAY HAVE IMPAIRED CAPACITY?

We treat this question as a legal question, and one with a legal answer, involving questions of degree that depends on the time at which it is asked. Planning for the future is predicated on assumptions of competency. Formally, competency in this sense is a legal conception: a person who executes a power of attorney, a trust or a will must

⁶ Ibid.

⁷ L Gostin, ‘Human Rights of Persons with Mental Disabilities: The European Convention of Human Rights’ (2000) 23(2) *International Journal of Law and Psychiatry* 125, 126.

⁸ C Bigby, *Moving on Without Parents: Planning, Transitions and Sources of Support for Middle-Aged and Older Adults with Intellectual Disability* (MacLennan & Petty, 2001) 71-2.

⁹ *Social Security (Administration) Act 1999* (Cth) Part 3A, ss 123A-123S.

¹⁰ ‘The conceptualization of mental health as a human right, and not simply a moral claim, suggests that states possess binding obligations to respect, defend, and promote that entitlement. Considerable disagreement, however, exists as to whether “mental health” is a meaningful, identifiable, operational, and enforceable right, or whether it is merely aspirational or rhetorical ... international human rights bodies have not developed a clear definition that helps clarify state obligations, identify violations, and establish criteria and procedures for enforcement’: Gostin, above n 7, 158.

be legally competent to do so. Competency is required in planning, finalising and conducting arrangements: in other words, both now and in the future. But competency can be impaired by a very diverse set of factors that can make planning complicated and difficult. Some of these factors are likely to have a present and ongoing impact on the competency to plan, such as developmental disability. Some can impact after planning has been conducted, such as acquired brain injury or dementia. Chronic mental illness can eliminate competency, but 'lucid intervals' give rise to the prospects of increased involvement and personal management of legal and financial affairs. Because of the diverse ways in which competency can be diminished, a person who is competent today may not be competent tomorrow. In short, any person in Australian society is a person who may have or may develop impaired capacity that can affect their capacity to make decisions.

The rise in the number of ageing people with cognitive disabilities is a relatively recent trend. Many factors contribute to this. In part it is because of the significant increase in life expectancy over the last 50 years: more people with developmental impairments are living longer,¹¹ and a higher proportion of previously unimpaired individuals are living to the more advanced ages¹² where the population incidence of dementia begins to climb steeply.¹³ So far as the latter group is concerned, forecast future numbers are inevitably boosted by the demographic ageing (and sheer size) of the 'baby boom' generation. As a proportion of the population, people aged over 65 years grew from 8 per cent in 1971 to 13 per cent by 2002 (or 2.5 million) which will double again to a projected 25 per cent (or 6.2 million) by 2042.¹⁴ For people in Australia aged 85 and over, the growth is even more rapid, from 300,000 in 2002 to 1.1 million in 2042.¹⁵ This rise in the number of 'old old' people redoubles the planning challenge: these people are more likely to develop cognitive disabilities and have more limited informal care networks.

Difficulties are associated with the determination of the exact size of that subset of people who are ageing and who have not one, executed plans for their own future; and/or two, executed plans for a person they care for.¹⁶ Further difficulties in identifying the pool of people with impaired capacity who need plans arises from the fact that they and their carers may not be 'aged' yet, which means that planning for the future is either 'off the radar' and/or they use services where planning is not discussed

¹¹ C Bigby, 'Ageing with a Lifelong Disability: Challenges for the Aged Care and Disability Sectors' (2002) 24(4) *Journal of Intellectual & Developmental Disability* 231, 231.

¹² Life expectancy for males at birth was 68 years in 1960, it has already risen to 78 years and by 2042 it is expected to be 83 years: Australian Government, The Treasury, above n 3, 20.

¹³ Access Economics, above n 4; C Tilse et al, 'Families, Asset Management and Care Giving: Developing Issues in Policy, Research and Practice' (Paper presented at the 8th Australian Institute of Family Studies Conference, Melbourne, 12-14 February 2003) 2 <<http://aifs.org.au/institute/afrc8/tilse.pdf>> at 9 January 2007.

¹⁴ Australian Government, The Treasury, above n 3, 18, 21; T Carney and S Sceats, 'Retirement Security in Australia' (Paper presented at the 8th Asian Regional Conference of the International Society for Labour and Social Security Law, Taipei: 31 October – 3 November 2005); T Carney, 'Ageing and the Law' in Alan Borowski, Sol Encel and Elizabeth Ozanne (eds), *Longevity and Social Change in Australia* (2007) 363-85.

¹⁵ Australian Government, The Treasury, above n 3, 21.

¹⁶ C Bigby, 'A Demographic Analysis of Older People with Intellectual Disability Registered with Community Services Victoria' (1994) 19 *Australia and New Zealand Journal of Developmental Disabilities* 1, 8.

or raised as an issue. However acknowledging that there is some difficulty in identifying the precise number of people involved, the figures available clearly demonstrate that the number of people who either have a disability, or are ageing, or both,¹⁷ will rise in coming years.¹⁸ The upshot of this is that the total number of people requiring plans for the future is very likely to rise.¹⁹

In 2003, there were almost 2.6 million unpaid carers in the Australian community; the majority of whom were women,²⁰ and approximately 18,000 were primary carers under the age of 25.²¹ However, the ageing population combined with the increasing workforce participation of women means a large discrepancy is likely to emerge between the number of people requiring care and the number of informal carers available to meet these needs.²² Between 2001 and 2031, the number of aged persons likely to require care because of a severe or profound disability (a category likely to be coextensive with impaired capacity as it is defined above) is projected to rise by 160 per cent, with the number of carers for this same period expected to increase by only 57 per cent.²³ This anticipated shortfall in the number of carers is likely to increase reliance on formal community care and/or various forms of residential care.²⁴ Pressure on the formal system is likely to create further pressure on informal systems.

People with developmental disability (and their informal parental carers) constitute the largest sub-set of people with such life-long care needs, and their contribution alone will increase by nearly 70 per cent in the next two decades.²⁵ Yet legal planning for the replacement of the informal care and support provided by parents and other family carers who are now likely to pre-decease the person cared for is especially challenging

¹⁷ Tilse et al, above n 13, 2; C Bigby and S Balandin, 'Another Minority Group: Use of Aged Care Programs and Community Leisure Services by Older People with Lifelong Disability' (2005) 24(1) *Australasian Journal on Ageing* 14, 14.

¹⁸ Australian Institute of Health and Welfare, *Disability and Ageing: Australian Population Patterns and Implications* (2000) quoted in G Llewellyn et al, 'Invisible Carers Facing an Uncertain Future' (Sydney: Faculty of Health Sciences, University of Sydney, 2003) 1: 'The total increase between 2000 and 2006 for people with a severe or profound core activity restriction is projected to be 11.6% mainly due to the rapid increase in the age groups 45-64 (19.3% or 59, 500 people) and 65 and over (15% or 76, 300 people)'.

¹⁹ Tilse et al, above n 13, 2.

²⁰ Australian Bureau of Statistics (ABS), *Disability, Ageing and Carers Australia* (Cat no. 4431.0.55.001, 2004), 10-11.

²¹ D Noble-Carr, *Young Carers Research Project: Final Report* (Canberra: Department of Families, Community Services & Indigenous Affairs, 2002) para 4.2 <http://www.facsia.gov.au/internet/facsinternet.nsf/disabilities/carers-young_carers_report.htm> at 12 February 2007. Indeed, one in ten young people between 15 and 25 exercise some level of carer responsibility: para 5.1.

²² Irish research found that such extensive reliance on informal family care of people with intellectual disability continued even in the face of great strides made in the UK in the provision of alternative housing options and support services, bearing out the international experience of a preference for extensive reliance on family care: R McConkey, 'Fair Shares? Supporting Families Caring for Adult Persons with Intellectual Disabilities' (2005) 49(8) *Journal of Intellectual Disability Research* 600, 600.

²³ National Centre for Social and Economic Modelling, *Who's Going to Care? Informal Care and an Ageing Population* (University of Canberra, 2004) 26, 28 <http://www.natsem.canberra.edu.au/publications/papers/otherpubs/informal_care/care_report.pdf> at 8 February 2007.

²⁴ Productivity Commission, *Economic Implications of an Ageing Australia* (2004) 7, 7.7.

²⁵ Bigby and Balandin, above n 17, 14.

for groups like the developmentally disabled. Replacement of the parental carer role is especially important here because people with an intellectual disability are often incapable of providing legal instructions.²⁶ But this may not be done due to the number of factors influencing whether and how to plan, issues such as:²⁷

the changing needs of carers, support to continue caring, planning for the transition from parental care and replacement of parental caring roles.²⁸

Parents of adult children with developmental disability may be reluctant to start planning because they cannot contemplate their role as care giver ever coming to an end:²⁹

Their parental caregiving career does not start and end at a particular stage of the life cycle. It begins with the birth of their child and ends when they themselves die.

Chief among those planning factors for people with developmental disabilities is the very considerable age of most carers when they relinquish care of their disabled offspring:

[T]he average age of parents when they ceased to be primary carers was 86 years. Transition occurred in the majority of cases because of parental death, incapacity or a move by parents to supported accommodation. A pre-planned residential move from parental care while their parent was in good health account for only 10% of transitions, and family disputes caused the remaining 3%. At the time of their transition, half the adults had at least one parent alive.³⁰

In the case of older Australians who develop cognitive impairments such as dementia later in life, the carer is often their life partner, but such informal family care is again the mainstay, providing 80 per cent of such care without compensation, at a value estimated at A\$1.7 billion in 2002.³¹ People with acquired brain injury or chronic mental illness are less likely to have long-standing parental care arrangements to fall back on, and their life partners (if any) may not be in a position to provide care.

Not only is there variation in the sources (and capacities) of informal carers,³² but the economic resources accessible to the person needing care will also differ. Older people experiencing an onset of dementia are more likely to have accumulated some asset base

²⁶ P McGhee and L-M Saw, 'Chiselling the Bars: Acting for People with an Intellectual Disability' (2005) 43(9) *Law Society Journal* 61, 61.

²⁷ Bigby, above n 8, 3.

²⁸ Bigby, above n 11, 232.

²⁹ G Llewellyn et al, 'Older Parent Caregivers' Engagement with the Service System' (2004) 109(5) *American Journal on Mental Retardation* 379, 379.

³⁰ Bigby, above n 8, 82; McConkey, above n 22, 600.

³¹ Access Economics, above n 4, 47.

³² Of course the combined impacts of other socio-economic and demographic trends need to be borne in mind as likely to reduce the capacity for informal care over time, with Australian families becoming increasingly mobile, increasingly likely to be single-parent families, families becoming smaller in size and more likely to have both parents in the workforce, and families becoming more geographically dispersed: See L Hancock, 'The Care Crunch: Changing Work, Families and Welfare in Australia' (2002) 22(1) *Critical Social Policy* 119.

(if only in the form of home equity)³³ and may have built up savings by virtue of having participated in the workforce. A person with an acquired brain injury may have suffered the injury at work or in a motor vehicle accident, such that a 'lump sum' compensation or damages award may have been obtained. People with life-long disabilities are generally much less fortunate.³⁴ A person with a developmental disability, for instance, is unlikely to have accumulated assets or savings, and may be exclusively reliant on a social security pension for income support. People with chronic mental illnesses may have built up assets or savings prior to the onset of the condition, but they too are likely to be more heavily reliant on social security transfers. All groups will be differentially affected by a wide variety of other factors, such as inheritances or informal transfers of in-kind support which may or may not be accessible to them.

It is important to observe that not all of these people will be vulnerable. Gwynnyth Llewellyn and her colleagues remind us that there are older people with a disability in the workforce,³⁵ and given the varied causes of impaired capacity noted before, some people with impaired capacity may have some or even a strong degree of involvement in their planning. Respect for human rights makes us look for the least restrictive alternative. And not all carers will be vulnerable. Llewellyn and her colleagues have identified a diverse range of responses to the challenges that carers face in assisting people who need help with planning: some 'go it alone', others are 'reluctant users', some work as 'tandem partners' with services and others leave the services in charge.³⁶

However, while not all carers are vulnerable, many of them are, and all are likely to experience challenges to their capacity to plan for the future arising from their social context. Being a carer of itself is commonly a very demanding and draining task: one which leaves little time for planning. Carers are usually women,³⁷ and often single,³⁸ and are likely to suffer health problems.³⁹ Caring responsibilities impact on relationships both with the person cared for as well as time to maintain outside relationships. Carers often experience 'chronic physical tiredness and increasing emotional and psychological stress,' and can suffer social isolation, loneliness and depression.⁴⁰ And, carers are likely to have lost or foregone paid employment⁴¹ and leisure opportunities.⁴²

³³ Tilse et al, above n 13, 2; C Tilse et al, 'Older Peoples Assets: A Contested Site' (2005) 24 *Australasian Journal on Ageing* S51, S51.

³⁴ As Bigby and Balandin observed: 'living with a cognitive impairment or severe physical disability may impact on the need for informal supports, the degree of community inclusion achieved during the individual's life, and the level of financial security available in old age': Bigby and Balandin, above n 17, 14.

³⁵ G Llewellyn et al, 'Promoting Healthy, Productive Ageing: Early, Plan Well' (2004) 29(4) *Journal of Intellectual & Developmental Disability* 366.

³⁶ Llewellyn et al, above n 29, 393-4. See also Bigby, above n 8, 3: 'as a group, ageing parents are not well connected to formal service systems and receive little formal assistance with the tasks of caring'.

³⁷ J Hailstone, 'Tender Loving Care' (1988) 2(4) *Interaction* 9.

³⁸ Ibid.

³⁹ K Barnett and R Shultz, 'Innovative Service Delivery Models Lessons Learned in Providing Care for Older People and People with Disabilities' (1990) 12(3) *Australian Journal on Ageing* 9, 11; J Englehardt, T Brubaker and V Lutzer, 'Older Caregivers of Adults With Mental Retardation: Service Utilization' (1988) 26(4) *Mental Retardation* 191, 191.

⁴⁰ T Cluning, 'Ageing People Giving and Receiving Care' in Theresa Cluning (ed), *Ageing at Home: Practical Approaches to Community Care* (2001) 95, 100.

Older parents suffer from anxieties that are often unknown to their younger counterparts. These include:

- ‘unending dependency,
- chronic sorrow,
- declining physical capacity,
- lack of formal services,
- social isolation,
- financial pressures and
- anxiety about the future care of their offspring’.⁴³

Reluctance to relinquish is an issue we address later in this paper. In addition to this, older carers are more likely than their younger counterparts to be sole carers, live in smaller households and to have smaller informal support networks. Older parents experience greater satisfaction from caring than their younger counterparts, but while often anxious about the future, they are more distrustful and ‘out of touch with’ formal arrangements and so are less likely to engage in formal concrete planning.⁴⁴

A strong case is made by USA and UK researchers to proactively engage with older carers, drawing them into formal support systems to support planning for the future. It is suggested that timely intervention will assist in preparing adults with intellectual disability for transition from parental care and greater interdependence, support parents to renegotiate their caring role avoid unplanned transitions and help predict future formal support needs.⁴⁵

The emphasis on community rather than institutional or government care, combined with the demographic changes outlined above, has necessitated a shift in responsibilities away from the public sector towards families and friends providing care for the aged on an unpaid basis.⁴⁶ Families are by far the most significant provider of care to the aged, with 80 per cent of care being provided by family members living in the same household as the care recipient.⁴⁷ Almost half of those receiving informal care are aided by partners, although adult children also provide significant assistance with tasks

⁴¹ Ibid.

⁴² J Jennings, 'Elderly Parents as Caregivers for Their Adult Dependent Children' (1987) 32(5) *Social Work* 430, 430.

⁴³ C Bigby and E Ozanne, 'Comparison of Specialist and Mainstream Programs for Older Carers of Adults with Intellectual Disability: Considerations for Service Development' (2004) 57(3) *Australian Social Work* 273, 274.

⁴⁴ Ibid.

⁴⁵ Ibid 275.

⁴⁶ V Minichiello and I Coulson, 'Family Support and Community Care in an Ageing Society.' (1999) 52 *Family Matters* 34. See also Llewellyn et al, above n 18, ii, 3: For over eight in ten people with severe disabilities the main provider of care is an informal community carer. But carers too are ageing, and have often been undertaking the role for many years. Four in ten carers have been providing care for a decade, and one in ten for a quarter of a century. Women, increasingly women living alone with the person cared for, disproportionately carry that burden of care. The time devoted to caring is substantial. As Llewellyn and colleagues found, 'for carers caring for 25 years and over, half (50.2%) spend no less than 20 hours a week caring and the majority of these carers (76.2%) spend over 40 hours a week devoted to caring activities'.

⁴⁷ C Millward et al, 'Family Care' in David de Vaus and Irene Wolcott (eds), *Australian Family Profiles - Social and Demographic Patterns* (1997) 107, 116.

including property maintenance, health care, transport, housework, mobility and personal care.⁴⁸

The majority of parents ... wanted to continue to care for their adult child as long as possible. They envisaged that plans for future care would not be implemented before their death or inability to continue caring. Several informants suggested that the reason for this was the deep bond between parents and their adult child and the interdependence developed between them in later life. As parents aged, the degree of support provided was often matched by support received from their adult child, leading to a finely balanced reciprocal care situation.⁴⁹

In many cases, parents and carers engage in some form of informal planning. When they do so they tend to see planning as a matter of establishing the identity of another person, typically a family member (i.e. a sibling of their ageing child) who will take over as 'successor caregiver',⁵⁰ in what Chris Bigby calls 'key person' planning. Key person succession plans are commonly developed by carers of developmentally disabled people (nearly 7 of 10 in some surveys) and involve the 'planned transfer of responsibility for overseeing the wellbeing of the person with intellectual disability to some other nominated person or persons'.⁵¹ Implicit key person succession plans, for their part are:

[T]he unspoken expectations that parents held of others about the roles they would assume in the future... This type of plan, however, involved more than just hope. The nominated person was usually strongly aware of parental expectations and had implicitly accepted them. In one sense, these plans were minimal but, in another, were open ended and had enormous scope. When an implicit key person succession plan was made, it was generally the only sort of plan a parent has formulated.⁵²

We now turn to consider the typical legal needs of carers of people with impaired capacity, particularly older carers.

II THE LEGAL NEEDS OF OLDER PARENTS OR CARERS

Older parents or carers often need to plan for the future care of their child. This need can arise in a number of ways: on the death of the parent or carer; if the parent or carer becomes too sick or weak to take care of the person with cognitive disability; or if the resolve of the parent or carer to care for the person fluctuates.⁵³ The death of a partner may also precipitate difficulties.⁵⁴ Unfortunately, the social services system is often only turned to in the event of a crisis (or imminent crisis) affecting the ability of the parent or carer to provide care. In the event that such a crisis occurs, the person with a cognitive impairment may suffer the doubled emotional trauma of losing their carer and

⁴⁸ ABS, n 20, 9.

⁴⁹ Bigby, above n 8, 76.

⁵⁰ A phrase coined by M Mailick Seltzer et al, 'Cross-national Comparisons of Ageing Mothers of Adults with Intellectual Disabilities' (1995) 39(5) *Journal of Intellectual Disability Research* 408, 414.

⁵¹ Bigby, above n 8, 71.

⁵² Ibid 72.

⁵³ Seltzer, above n 50, 409.

⁵⁴ See S Todd et al, 'Careers in Caring: The Changing Situations of Parents Caring for an Offspring with Learning Difficulties' (1993) 14(1) *Irish Journal of Psychology* 130, 131.

entering an inappropriate residential placement because of a lack of planning and/or a lack of available and appropriate service options.⁵⁵

To circumvent these crises, it is necessary for older parents and carers to plan for the future. Some do, but many do not. Bigby notes the importance of adequate future planning for people with intellectual disabilities: 'it ... can avert the crisis of an ill-prepared transition from parental care, ensure longer term security and stability of the persons with intellectual disability, and forecast future service demands'.⁵⁶ Bigby recommends that plans should be flexible and adaptable to meet changing circumstances, but notes that they serve multiple social functions; including facilitating the transition from parental care and ensuring longer term quality of care for the person with a cognitive disability as they age. These plans may also seek to provide for ongoing cost sharing of future care between parents and the State.⁵⁷ Thus:

Parental plans value protection and permanency rather than developmental opportunities. Instead of looking towards increased independence for their adult child in the future, parents seek residential accommodation to duplicate the care and protection that they have provided at home.⁵⁸

Planning for the future is a multi-faceted question, covering issues already experienced, those expected to arise in the future, and the marshalling of needed outside assistance. The capacity of parents or carers to plan for the future varies in accordance with individual circumstances, and the involvement of outsiders is often necessary and desirable to enhance its success.

Our own previous study,⁵⁹ based on a survey of 185 service providers, parents and carers, disability discrimination and welfare legal centres, government organisations and advocacy groups, supplemented by key informant interviews, found that nearly three quarters of carers of ageing people with impaired cognitive capacity had already encountered issues such as making wills (18.2%), applying for guardianship (15.6%), making complaints about services (including guardianship) or advocating for better services (11.7%), monitoring or providing consent to medical treatment (6.5%), or obtaining power of attorney with respect to matters involving property or financial management (5.2%).⁶⁰ Higher proportions anticipated encountering such issues in the future.

Planning for people with impaired capacity needs to be done by people who are competent in the legal and practical sense of that word. However people with disabilities and their carers need ready access to legal services, but find it difficult to access legal services and to obtain appropriate legal advice. Barriers to be overcome include cost, availability (including ease of contact), locality and sensitivity (or capacity to provide 'caring advice'). Other desirable professional qualities are experience with disabilities issues, perceived independence, ability to communicate in plain legal

⁵⁵ A V Kaufman, J P Adams and V A Campbell, 'Permanency Planning by Older Parents Who Care for Adult Children With Mental Retardation' (1991) 29(5) *Mental Retardation* 293, 293.

⁵⁶ Bigby, above n 8.

⁵⁷ Ibid 15.

⁵⁸ Ibid 17.

⁵⁹ Keyzer, Carney and Tait, above n 5, 18-19.

⁶⁰ Ibid.

language, reliability, flexibility to changing circumstances, and the reduction of complexity.⁶¹ The concerns of clients can be broadly characterised as *access problems*, *defective referral* and *inadequate services*.⁶²

Our previous exploratory survey research also indicated that there may be a need to clarify the role of the family and the State in this area.⁶³ A view which was shared by many of the survey respondents was that even though being a parent of an ageing son or daughter with intellectual disabilities involved self-sacrifice, many parents rejected the role of the State in parenting and any suggestion that their child should leave the family home. Very few believed that their offspring would be able to cope with independence, and some treated their adult children as 'eternal' children.⁶⁴ This is an issue that must be anticipated and constructively worked through during the planning process, rather than portrayed as an 'obstacle'. It is necessary to recognise the central role of parents in providing prolonged and intense care – care which can last 30, 40 or over 50 years.⁶⁵ Not surprisingly, these parents and carers are the central people in the lives of adult children with intellectual disabilities.⁶⁶ Parents who have been taking care of their adult children for a very long time experience loss when their child becomes independent and leaves home. These feelings of loss may be increased in circumstances where the parent has been caring for their son or daughter for 30 to 50 years. Parents of adult children with intellectual disability perceive themselves as being essential to the well-being of their children.

Planning for the future is a very challenging task, given the complexity of institutional and financial arrangements about pensions, superannuation residential care and so forth.⁶⁷ One of the many mistakes which can be made in thinking about the role of carers in planning is to assume that legal planning is a discrete, specialist service which is unrelated to other service systems and community life. It is a mistake because research demonstrates that the bulk of the population prefer to manage informally where possible. As Cheryl Tilse and her team found when examining asset management among the elderly, family members play a significant role in looking after this aspect of the lives of ageing family members. That management role is discharged through both formal means like enduring powers of attorney and informal arrangements such as '[customary understanding] arrangements with banks, signing blank cheques and using automatic teller machine pin numbers'.⁶⁸

⁶¹ Ibid 19.

⁶² S Ellison et al, *The Legal Needs of Older People in New South Wales* (Law and Justice Foundation of New South Wales, 2004) xvi-xvii.

⁶³ Keyzer, Carney and Tait, above n 5, 18-19.

⁶⁴ G Llewellyn, 'Family Care Decision-making in Later Life: The Future is Now!' in Mike Nolan et al (eds), *Partnerships in Family Care: Understanding the Caregiving Career* (2003) 145-46.

⁶⁵ In their 1996 Demand Study, the Australian Institute of Health and Welfare estimated that 'almost half of the 7,700 parents aged 65+ have been caring for the person with severe or profound handicap for 30+ years': Institute of Health & Welfare (AIHS), 'Commonwealth / State Disability Agreement Evaluation: The Demand Study' (Supporting Paper No. 2, AIHS, 1996) 35.

⁶⁶ S F Kriger, *Life Styles of Aging Retardates Living in Community Settings in Ohio* (Psychologia Metrika, 1975) quoted in D M Goodman, 'Parenting An Adult Mentally Retarded Offspring' (1978) 48 *Smith College Studies in Social Work* 209, 212.

⁶⁷ Tilse et al, above n 13, 2.

⁶⁸ Ibid 3.

While there is an inevitable level of abuse associated with such informal arrangements the authors found that it generally reflected ‘ignorance, confusion and lack of support rather than intentional abuse’, with some asset managers reporting that they ‘would welcome advice and support in these tasks (managing finances of older family members) and better safeguards.’⁶⁹ In light of this, Tilse and her colleagues argue that asset management should be reconceptualised as a community or social service issue rather than as a legal question:

Conceptualising asset management as a care giving task rather than solely linking it to discourse of adult protection/substitute decision making draws attention to the resources, support, information and monitoring carers need to do it properly.⁷⁰

A number of private planning tools are potentially available to assist this task, along with the statutory machinery of adult guardianship laws. We summarise them in the next section of the article. Critically, though, services should attempt to work with families. In addition, this informal service planning can often provide the best future for the person who is being cared for. However, in some circumstances, informal support networks may need to be supplemented. Where none exist, services may need to be provided. There may also be a need for effective monitoring and review of the circumstances in the interests of the individual.

III LEGAL TOOLS TO ASSIST IN FUTURE PLANNING

A *Private Legal Planning Options for People with Cognitive Disabilities*

There are a number of private legal options available to older parents or carers who wish to make such provision for ageing people with cognitive disabilities, including:

- Wills and estate planning (including ‘living wills’);
- Powers of attorney; and
- Trusts (including ‘organisational’ trusts).

Solicitors may draw up wills and trust arrangements on behalf of their clients who are ageing parents or carers of people with a cognitive disability, though, as discussed later, there are questions regarding the cost and availability of making these arrangements. The main questions apart from sound legal and financial planning are whether the instrument also meets disability goals of the person with a cognitive disability such as the principles of the ‘least restrictive alternative’, ‘assurance of non-discriminatory access to generic services,’ and protection of the client’s property, assets and resources.⁷¹

⁶⁹ Ibid 4.

⁷⁰ Ibid.

⁷¹ H Stanley, ‘Legal Processes and the Least Restrictive Alternative’ in Janicki, Matthew and Wisniewski, Henryk (eds), *Ageing and Developmental Disabilities: Issues and Approaches* (1985), 77.

1 *Wills*(a) *Standard wills*

A 'standard will' is a declaration of intention concerning matters which the testator, or maker of the will, desires to take place on or after his or her death.⁷² It is undoubtedly the most common form of formal planning undertaken by parents and carers.⁷³ Typically the home or other assets are left to a sibling or relative, on the understanding (express or implied), that they will assume responsibilities as 'successor caregiver' for the person with the cognitive disability.⁷⁴ There are clear advantages in relying on a family member with some special knowledge of the person. However it forecloses other management options which might better secure financial and social outcomes for the person, and may fail to take account of changed circumstances of either party.

Implied understandings can be problematic, of course. As Stephen Booth writes, it:

shows a lack of imagination about the uses to which a share of the estate could be put by the person with the disability or a trustee on his or her behalf, and sometimes the sibling takes a narrow view of what needs to be done. Wills in this form are vulnerable to a Family Provision Act claim.⁷⁵

After the death of the parent or carer, other family members may challenge the will, or feel sufficiently aggrieved about being slighted as to reduce their previous levels of informal contributions to care needs. In short, there is no guarantee of an ongoing commitment to care, and no obvious mechanism for review of the situation. Guardianship boards frequently comment on this matter in examining the financial situation of a person for whom an administration order is proposed.⁷⁶

(b) *Living wills*

Another defect of the standard will is that it provides no assistance in situations where the ageing parent or carer has lost capacity before death. In this situation, a 'living will' allows a person to make provision for the care and support of another family member, with the 'triggering event' being an event such as incapacity (of the person making the living will) rather than their death. These have been developed in various Canadian provinces, and are available in New Zealand guardianship legislation.⁷⁷

⁷² Adapted from *Lee's Manual of Queensland Succession Law* (LBC Information Services, 5th ed, 2001) 11.

⁷³ S Booth, 'Providing for a Child with an Intellectual Disability' (1996) 34(1) *Law Society Journal* 63, 63.

⁷⁴ Seltzer, above n 50.

⁷⁵ Booth, above n 73, 63.

⁷⁶ Cases where this has arisen include: *Re GE* [2005] QGAAT 32 paras 139-46 [family conflict regarding sale of property in which intellectually disadvantaged person residing pursuant to mother's will]; *Re MAC*, [2006] QGAAT 43, paras 33-7 [conflicts of interest when family provision application pending]; *Re BNA*, [2005] QGAAT 73 [conflict between parents of intellectually disadvantaged person].

⁷⁷ *Ibid.*

Living wills can also be valuable in identifying preferred service options, indicating possible providers, and providing some reassurance to the parent that their views will be a central part of any future planning process. They can also make financial provision for the adult child during the period between incapacity and death of the carer. The process of drawing up the plan can itself be a valuable exercise, and generate some commitment to its implementation. In particular the provision of financial support for ongoing housing needs could help to ensure that the adult child has some security of tenure. These might be handled through a trust (see below).

However, while reforms ensuring the availability of living wills in Australia might be desirable, in this context living wills share the problems which can beset other testamentary arrangements. Situations can change in unforeseen ways, and the needs of an adult child may be quite different when the plan is made from the time it is expected to come into effect.

2 *Powers of attorney*

A power of attorney is a second type of private planning arrangement which enables one person to appoint another person to act on his or her behalf in matters involving the management of property or finances.⁷⁸ A variant, the enduring power of attorney, continues to be effective if a person loses competency.⁷⁹

(a) *Ordinary power of attorney*

Ordinary powers of attorney can be useful where a parent or carer wishes to delegate (or share) some aspect of their own powers with a chosen person or professional. This might arise where the person wishes to leave someone in charge when taking an overseas trip or holiday which will take them away from the daily activities and needs of their adult child. Or it may recognise that the complexity of the issue is beginning to tax their own knowledge or energy.

However, to have legal effect, the parent or carer must understand the nature and effect of the power which they are delegating, and must remain legally competent to do so. This is because an ordinary power of attorney ceases to be valid once the person who executed the document slips below the level of legal capacity required by the law to validly execute such an instrument in the first place.⁸⁰ This means that in practice it is unlikely to be used by an older person or carer as a long-term planning device. It ceases to operate at precisely the point it would be needed – the time when the parent or carer is no longer able to cope.

⁷⁸ See *Powers of Attorney Act 1998* (Qld) ss 8, 11-14.

⁷⁹ *Powers of Attorney Act 1998* (Qld) s 32(1) [enduring power in respect of financial or personal matters].

⁸⁰ T Carney, 'Abuse of Enduring Powers of Attorney: Lessons from the Australian tribunal experiment?' (1999) 18 *New Zealand Universities Law Review* 481; *Gibbon v Wright* (1953) 91 CLR 423, 445; *Drew v Nunn* (1879) 4 QBD 661, 666.

(b) Enduring powers of attorney

Enduring powers of attorney, for example under section 32(1) of the *Powers of Attorney Act 1998* (Qld) enables the person appointed by the parent and/or carer to use their property or money for the benefit of the ageing child after the person setting up the arrangement loses competency. However it is of no assistance in meeting the primary social goal of many parental carers, concerned to see continuity in the 'parental' care they have been exercising (without legal authority)⁸¹ and which they are reluctant to contemplate altering in the future.⁸²

A remarkable feature of these parents' lives is that they rarely think of themselves as caregivers. Instead they see themselves as parents caring for a child. They talk about their sons and daughters, regardless of their adult status, as still being their children. They refer to their duty, no matter what the circumstances, as being to parent or 'look after' their child.⁸³

Enduring powers of attorney, even one covering 'personal matters' rather than property, is of no assistance at all in realising this wish to delegate 'parenting' powers, since parents of adult children have no formal guardianship responsibility to hand over. Such rights can only be conferred on a parent or another adult by a personal guardianship order made by the Queensland Guardianship Tribunal, or through the exercise of its power to 'ratify' the informal exercise of such powers on the part of a person's 'support network' as defined.⁸⁴

Even when an enduring power is an option, people can be unwilling to use them unless they are accessible and 'easy' to use.⁸⁵ Research has shown that jurisdictions which have gone to lengths to introduce 'formalities' and other protections in an endeavour to stamp out 'abuse', end up with unduly low rates of usage of enduring powers, because these measures 'discourage people from assuming this responsibility for asset management or encourages a resort to informal or illegal strategies that put both the older person and the person assisting them at risk'.⁸⁶ Access to information in a form able to be readily understood is vital:

⁸¹ See for instance: T Carney, 'Civil and Social Guardianship for Intellectually Handicapped People' (1982) 8(4) *Monash University Law Review* 199; T Carney, 'Aged Capacity and Substitute-Decisionmaking in Australia and Japan' (2004) 2003/4 *LawASIA Journal* 1.

⁸² Llewellyn et al, above n 29, 379.

⁸³ Llewellyn, above n 64, 145-46.

⁸⁴ *Guardianship and Administration Act 2000* (Qld) ss 32(1) [enduring powers for financial or personal matters], 9(1), 154 [ratification of informal decisions]. A person with a cognitive disability could execute an enduring power of attorney which delegated their *own* self-management powers over their person (or their finances), but in Queensland the order would only be valid if they had the 'capacity' to understand its nature and effect, the ability to freely and voluntarily choose and to communicate that choice to make that delegation: *Powers of Attorney Act 1998* (Qld) Schedule 3 definition of capacity, identical definitions appear in the *Guardianship and Administration Act 2000* (Qld), Schedule 4 definition of capacity. So in practice this excludes this avenue for virtually all people with cognitive disabilities.

⁸⁵ T Carney, 'Globalisation and Guardianship: Harmonisation or (Postmodern) Diversity?' (2001) 24(2/3) *International Journal of Law and Psychiatry* 95, 103; T Carney and D Tait, *The Adult Guardianship Experiment: Tribunals and Popular Justice* (Federation Press, 1997).

⁸⁶ Tilse et al, above n 33, S52.

The ability of older people to make informed legal choices may be circumscribed at a general level by lack of knowledge of the law and legal rights, limited access to legal services and prohibitive legal costs and ageist assumptions concerning the needs and capacities of older people.⁸⁷

Older people's capacity to make informed choices in the area of substitute decision-making may be circumscribed by difficulties in accessing information and confusion about the nature of enduring powers of attorney provisions.⁸⁸

On the other hand, concern has been expressed about the susceptibility of private arrangements to abuse and lack of scrutiny. Such arrangements may not be subject to the protective oversight of guardianship boards or tribunals.⁸⁹ Setterlund et al describe disability as a 'structural factor', which is capable of producing disadvantage, particularly 'in relation to the law in terms of lack of access to information, lack of knowledge of the law (and for some, the existence of the law), mistaken belief about the nature of the law, and feeling the need to cede control to families or professionals'.⁹⁰ Sensitivity to the spectrum of community values is also essential:

Current policy concepts of individuals having the financial means and the necessary will to plan for retirement largely reflect middle class, Anglo-Australian values. For many participants with lower incomes and for many from Indigenous and culturally diverse backgrounds, the idea of financial and future planning was not highly valued and consequently provision for substitute decision-making in relation to financial and health matters was viewed as largely irrelevant to their circumstances.⁹¹

As far as policy development in this area is concerned, the authors suggest that community awareness generally and in the 'older community in particular regarding both the advantages and disadvantages of substitute decision-making arrangements' needs to be raised.

It is crucial that older people understand that financial abuse may occur with or without formal arrangements in place and that insisting on participation in the ongoing management of their affairs is not an affront to the trust they place in families to act in their best interests.⁹²

3 *Trusts*

Trusts enable property and funds to be managed by someone (the 'trustee') in the interests of another (the 'beneficiary'). They may be established either during a person's lifetime, or may be created in a will. Trust instruments may describe what is to be done in significant detail, or may empower the trustee to expend monies in their discretion.

⁸⁷ D Setterlund, C Tilse and J Wilson, 'Older People and Substitute Decision-Making Legislation: Limits to Informed Choice' (2002) 21(3) *Australasian Journal on Ageing* 128, 128.

⁸⁸ *Ibid.*

⁸⁹ *Ibid.*

⁹⁰ *Ibid* 132.

⁹¹ *Ibid.*

⁹² *Ibid.*

(a) Discretionary trusts

As Stephen Booth comments:

If a trust is used, a discretionary trust is usually the best choice. Since the person with the disability may often have the same life expectancy as a person without a disability and have changing needs and abilities over time, and as government-funded accommodation services, social security law and tax law may change, a broad discretion will enable a trustee to meet changes as they occur. The disadvantage is that giving a trustee a very broad discretion makes it difficult to control the trustee's exercise of discretion.⁹³

'Discretionary' trusts may have certain advantages as financial planning devices. Because they allow, but do not require, the trustee to distribute funds for the beneficiary, they may have tax-minimisation advantages. However, until the passage of the 'special disability trusts' provisions inserting Part 3.18A of the *Social Security Act 1991* (Cth) with effect from 2006, such arrangements were of little or no advantage in minimising income or assets for social security purposes, and as explained elsewhere, the amendments do little to change this due to their very narrow ambit.⁹⁴

(b) Choosing trustees

The choice of trustee(s) is obviously quite critical however. The trustee should be young, prudent, independent and interested in the beneficiary.

Individual testators will have their own aspirations for their children with an intellectual disability and their abilities and circumstances will vary from case to case. A parent who wants their child to live in the least restrictive environment possible will be ill-served by a trustee who believes that people with an intellectual disability automatically require institutional living. It is fundamental that the parents should be confident that the trustee they choose will as nearly as possible implement their own wishes for the child. The testator should be encouraged to discuss the issues with the proposed trustee to ensure confidence is well placed.⁹⁵

(c) Service trusts

Service trusts are a popular planning device in some countries. Service trusts involve parents coming together to pool resources. Generally this is done by creating an advocacy organisation independent of service providers which then takes on responsibility for a number of individuals: undertaking to house them, provide activities, supervise medical care and maintain a services plan. Agency schemes generally involved a cooperative trusteeship which employed administrative staff or advocates to meet needs without resorting to legal powers.⁹⁶

⁹³ Booth, above n 73, 63.

⁹⁴ T Carney and P Keyzer, 'Private Trusts and Succession Planning for the Severely Disabled or Cognitively Impaired in Australia' (2007) 19(2) *Bond Law Review* 1.

⁹⁵ Booth, above n 73; *ibid*.

⁹⁶ R Hodgson, 'Guardianship of Mentally Retarded Persons: Three Approaches to a Long Neglected Problem' (1973) 37 *Albany Law Review* 407, 430.

The main difficulty with service trusts in Australia⁹⁷ is that they are caught by social security rules which continue to count the trust assets as property of the settlor, and which regard the services as monetary value (or an asset) for the purposes of the income security entitlements of intended beneficiaries. Some countries such as New Zealand empower their guardianship courts to make wider orders than mere personal or property guardianships – opening the possibility for leverage to be brought to bear to utilise available assets in such ways – but this would be of little assistance in Australia while social security rules operate in the way just described.⁹⁸

B *Public Sector Planning Options for People with Cognitive Disabilities*

Adult guardianship tribunals are the principal public sector tool able to be invoked in Australia to assist in planning for the on-going care of a person with a cognitive disability.⁹⁹

1 *Guardianship*

Adult guardianship involves appointing substitute decision makers for adults who lack capacity, and for whom there is no workable alternative. This alters a person's legal status. A person may be appointed to make decisions about business (property), or to deal with their personal affairs – such as where they live.¹⁰⁰

The tribunals are accessible and cheap,¹⁰¹ but they will not make an order unless it is essential to do so.¹⁰² As a result, anticipatory orders cannot be obtained by way of an 'insurance' measure. Further, guardians or financial administrators in most States can be appointed by the State only when there is a current need, so future planning is in general outside the mandate of the guardianship tribunals. Guardians, when appointed

⁹⁷ A difficulty not removed by the special disability trust reforms: Carney and Keyzer, above n 94.

⁹⁸ Victoria's Disability Review Panel (replaced from September 2007) previously adjudicated on citizen complaints about inadequacies in 'service plans' required to be drawn up to establish the levels of certain government services, while States like New South Wales also adopt a service plan approach to government services, but this is a quite different issue to that of marshalling private resources through service trusts: T Carney, 'Re-mixing "Access", "Advocacy", "Empowerment" and "Protection"? A Case for a Specialised Division of Labour in Guardianship, Mental Health and Disability Services Adjudication?' (2003) 5 *Newcastle Law Review* 43.

⁹⁹ Carney, 'Civil and Social Guardianship for Intellectually Handicapped People', above n 81.

¹⁰⁰ A useful summary of the Queensland legislation is available in Chapter 2 of Queensland Law Reform Commission, 'Confidentiality in the Guardianship System: Public Justice, Private Lives' (Discussion Paper, Queensland Law Reform Commission, 2006); see also Carney and Tait, above n 85.

¹⁰¹ Carney, above n 85, 104.

¹⁰² *Guardianship and Administration Act 2000* (Qld) ss 11 [application of 'general principles' in Schedule 1] 12. Among the principles laid out in Schedule 1 are the presumption of capacity (cl 1), participation in community life and encouragement of self-reliance (cl 5, 6) and that of 'maximum participation and minimal limitations (cl 7). The Tribunal has been assiduous in applying these guiding principles when deciding hard cases: see eg *Re JD* [2003] QGAAT14 [restraint to avoid self-harm]; *Re WAB* [2007] QGAAT 12 [least restrictive approach to lack of insight in Huntington's Chorea case]; *Re JGM* [2006] QGAAT 8 [informal arrangements for intellectually disadvantaged person not least restrictive]; *Re TAB* [2007] QGAAT 30 [parental use of seclusion for managing Rhatt Syndrome versus least restrictive independent living options].

to solve a current crisis, may set up longer-term planning arrangements, but this would cover a minority of situations where such planning is desired.¹⁰³

Another feature of the way adult guardianship works is that there is a strong preference to entrust the management powers to an appropriate individual where possible. While there is a statutory guardian of last resort, public sector agencies are necessarily more impersonal.¹⁰⁴ Therefore, guardianship is not able to maintain or re-establish close personalised management of a person with cognitive impairments in the event that there are no willing family members living close enough to provide the ongoing oversight.¹⁰⁵

There is also the dilemma that the most enthusiastic applicant for guardianship may not be the best qualified family member to undertake the work, and even the most appropriate applicant for guardianship may struggle to cope without ongoing advice and support. The effectiveness of family guardianship, then, is dependent on knowledge, assertiveness and skills to make complex decisions. Training and support to enable the development of these skills may be necessary.

2 Alternatives short of guardianship?

Queensland is one jurisdiction to give serious attention to alternatives short of resort to statutory guardianship. In addition to well developed avenues for appointment of personal, financial, or health attorneys in advance of loss of capacity,¹⁰⁶ Chapter 5 of the *Guardianship and Administration Act 2000* (Qld), clothes a pre-ordained 'list' of decision makers (called the 'statutory health attorney') with automatic authority to make certain health decisions,¹⁰⁷ while the legislation also gives effect to the 'intermediate' idea proposed by the Queensland Law Reform Commission,¹⁰⁸ of Tribunal ratification of informal decisions made (or to be made) by an incapacitated person's friends or 'support network'.¹⁰⁹

¹⁰³ T Carney, 'The Limits and the Social Legacy of Guardianship' (1989) 18 *Federal Law Review* 231.

¹⁰⁴ See for instance *Adult Guardian v Hunt* [2003] QSC 297; and in New South Wales: Public Bodies Review Committee, Parliament of New South Wales, *Personal Effects: A Review of the Offices of the Public Guardian and the Protective Commissioner* (2001).

¹⁰⁵ T Carney, 'Challenges to the Australian Guardianship & Administration Model?' (2003) 2 *Elder Law Review* 2 <<http://www.uws.edu.au/about/acadorg/clb/sl/research/elderlaw/elderlawreview/volume2>> at 11 July 2007. The challenge for the future 'may be to find creative ways of "personalising" guardianship services' for those who are excluded from the system: 5.

¹⁰⁶ *Guardianship and Administration Act 2000* (Qld) s 9(2)(b); *Powers of Attorney Act 1998* (Qld) s 32(1) [enduring powers in respect of financial or personal matters (including health matters other than special personal or special health matters)]; s 35(1) [advance health directives (s 35(1)(a), (b)) and/or enduring health power: s 35(1)(c), (d)].

¹⁰⁷ The list of statutory health attorneys starts with any spouse with a close and continuing relationship, followed by a carer (other than a paid carer) and friends: *Powers of Attorney Act 1998* (Qld) s 63. This definition of statutory health attorney is adopted for guardianship purposes: *Guardianship and Administration Act 2000* (see Schedule 4 definitions).

¹⁰⁸ Queensland Law Reform Commission (QLRC), *Assisted and Substituted Decisions: Decision-Making by and for People with a Decision-Making Disability* (1996). The Commission is presently reviewing the legislation once again. Some of the differences between the QLRC recommendation and the provision as enacted are explored in: B White and L Willmott, 'Will You Do As I Ask? Compliance with Instructions about Health Care in Queensland' (2004) 4(1) *Queensland University of Technology Law and Justice Journal* 77.

¹⁰⁹ *Guardianship and Administration Act 2000* (Qld) ss 9(1), 154.

Access to such options apart from formal orders made by the Guardianship Tribunal, including flexible provisions attuned to the informal environment of everyday life, increases the likelihood that the law will find favour in one of its several forms. As Carney and Tait have previously observed:

Ensuring that the 'least restrictive option' is chosen is not primarily a matter of better education, better investigation or thorough scrutiny of a person's situation. These are clearly important. But more critical is ensuring that less restrictive options are available in the broader guardianship system. In other words providing the structural conditions for greater personal freedom and autonomy for people with disabilities. Without these options, the last option of personal guardianship may become, for too many people, the only available option.¹¹⁰

C *Summary*

In sum, there are a number of private methods of planning for the future, backed up by access to the adult guardianship tribunal when needed.

Wills may be used to pass property, trusts can be created for ongoing care and management of property, and powers of attorney may allow delegation of powers by a care-giver to another person while they are alive and competent to do so. Planning issues are of great concern to parents, but private planning mechanisms offer limited solutions.¹¹¹ Thus, parents have no common law power to devise or entrust de facto 'parental' powers over many day-to-day care issues relating to their adult children – for example medical treatment. Statutory health attorney legislation such as that in Queensland is the only way such powers can be conferred.

Guardianship tribunals can make orders should an immediate need for medical care, money management or personal guardianship arise. However such powers will not be extended in *advance* of the need arising. And the quality of the outcomes will hinge on the availability of family members or friends willing to assume the job of being the substitute decision maker for the person with impaired capacity, or to accept the 'ready made' responsibilities made available under the statutory health attorney provisions.

Both private and public planning tools are restricted to working with whatever level of private assets or income held by the ageing parent or carer whose shoes they are called to fill. Not only are these resources often fairly limited, but the new guardian or carer often does not feel the same moral obligation to maintain the extensive commitments of voluntary time, support or care formerly provided by the aging parent or original carer. In other words, planning using public and private devices takes place in a practical social context. We briefly consider some aspects of that context in the following section.

¹¹⁰ D Tait and T Carney, 'Too Much Access? The Case for Intermediate Options to Guardianship' (1995) 30 *Australian Journal of Social Issues* 445.

¹¹¹ T Carney and K Akers, 'A Coffee Table Chat or a Formal Hearing' (1991) 2 *Australian Dispute Resolution Journal* 141.

IV SOCIAL REALITIES IN PROVIDING LEGAL PLANNING

All planning takes place in a social context. There are a number of issues that need to be taken into account by policy-makers and reflective practitioners. These include the need for independent advocacy to ensure the realisation of the human rights of all participants; the role of social services and private legal services as planning advisors; and the need to avoid financial abuse and mismanagement.

A *The Need for Independent Advocacy*

Planning for effective outcomes needs to be supplemented with effective advocacy which enhances client autonomy, wins the trust and confidence of parents and carers, and replaces parental brokerage of services with advocacy. Independent advocacy for the client is necessary, primarily to ensure that the person has the opportunity of learning independent living skills. People need to have the opportunity to take risks and to develop problem-solving skills.¹¹² To avoid service overloads, people should be trained for the transition from home to independence.¹¹³ Older people with intellectual disabilities need to be given opportunities to make choices and decisions about their lives.¹¹⁴ Yet they may rarely be given these opportunities.¹¹⁵

Independent advocacy is also needed in order to ensure the privacy of the parties concerned; to ensure their individual interests are being met; to guard against conflicts of interest; to improve the client's understanding of the operation of the law; to deal with issues relating to legal competency; to establish the nature of any 'special relationship' between members of a family; and to consider what the future holds.¹¹⁶

One of the ingredients sought by parents and carers is a sense of independence and expertise in the process used to make the decisions. People are looking for institutions in which they can confidently place their trust. The spectre of risky or abusive financial practices, which is considered further below, propels this concern. As parents consistently ask: 'Who will help when I'm gone?' Continuity of support is another factor to be considered.

B *Legal Services: Availability, Accessibility and Knowledge*

Previous research has suggested that respondents in need of a 'broker' to assist them with their needs turn to various sources. They seek out private solicitors for help with their legal problems, as well as turning to legal aid, a specialist advocate, a public

¹¹² A Ashman, 'Aging: Looking Towards Changes in Existing Services' (Paper presented at Quality and Equality in Intellectual Disability: Proceedings of the 29th Australian Society for the Study of Intellectual Disability (ASSID), National Conference, Newcastle, New South Wales, November 30 - December 5 1993) 25.

¹¹³ A Ashman, 'Older Australians with Intellectual Disability: The Survivors' (1994) 19(1) *Australia and New Zealand Journal of Developmental Disabilities* 25.

¹¹⁴ A Ashman and J Suttie, 'Changing Existing Services for Older People with an Intellectual Disability' (1995) 20(3) *Australia and New Zealand Journal of Developmental Disabilities* 189, 197.

¹¹⁵ *Ibid.*

¹¹⁶ H Eisenberg, 'Durable Power of Attorney v. Living Will: Counseling Older Clients' (1991) 79 *Illinois Bar Journal* 384, 385-6.

trustee organisation, a community advocate, a guardianship board or a social worker.¹¹⁷ It was rare for a community legal centre or disability discrimination legal centre to be contacted for advice, while those approaching a private solicitor, directly, usually knew what they wanted before they went.

These features suggest a need for better education: both to let clients know the range of services available, and to enhance the role of private practitioners in serving as part of an effective services referral network, given that such services are often the first point of contact for many with the legal system. However, planning tools are one thing. The knowledge and willingness of ageing parental carers to take advantage of them, and the capacity of professional advisers to assist them to utilise them well, are another matter entirely.

This is not simply due to a lack of information for, and communication between, carers and the profession (though this is part of it). Rather it stems from a lack of appreciation for the broader social context within which carers of cognitively impaired people have been operating. Queensland research has found that older carers are poorly informed about basic planning tools like enduring powers of attorney, even in situations where one had already been drawn up to cover their own affairs.¹¹⁸ Older people on lower incomes were found to lack sufficient information to equip them to seek advice about whether to execute such a document.¹¹⁹ Instead, there is a strong preponderance of informal arrangements based on trust within families. Older people felt most comfortable in ceding financial responsibility to their family, and in doing so express 'little interest in monitoring expenditures'.¹²⁰

When legal advice is sought, it frequently builds on strong personal qualities of the relationship with the lawyer:

Participants valued legal practitioners who were good communicators generally and who could communicate about legal terms specifically. For several participants the fact that their legal practitioner came to their home to provide advice on legal matters was important. Overall, the attributes of a good legal practitioner were thought to be: personal qualities of friendliness and warmth, good communication skills, respectful attitudes, expertise that demonstrated value for money and reasonable costs that were known beforehand.¹²¹

Costs, complexity of the law, the nuances and pitfalls in negotiating family dynamics, time taken on communication or assessing capacity, and barriers to easy access for clients – numbered among the reasons practitioners gave for limited provision of such advice to clients.¹²²

¹¹⁷ Keyzer, Carney and Tait, above n 5.

¹¹⁸ C Tilse et al, 'Legal Practitioners and Older Clients: Challenges and Opportunities for Effective Practice' (2002) 1 *Elder Law Review* 37 <<http://www.uws.edu.au/about/acadorg/clb/sl/research/elderlaw/elderlawreview/reviewvol1>> at 10 July 2007.

¹¹⁹ Ibid.

¹²⁰ Tilse et al, above n 33, S54.

¹²¹ Tilse et al, above n 118, 38.

¹²² Ibid 37-8.

When it comes to organising legal advice to facilitate planning by an ageing carer for the needs of a person with a cognitive impairment, these problems multiply. Not least of the added problems for aged carers of people with intellectual disability is that they do not envisage their role ending before their death, and they are reluctant to relinquish responsibilities prior to that point.¹²³ Despite the stresses of such care, older carers obtain greater satisfaction from its provision than is the case with younger carers, and are often ‘distrustful and out of touch’ with formal support services. Consequently ‘they are less accepting of the ageing process and their fear of death increases with age although anxious about the future care for their adult child, older parents are reluctant to engage in formal and concrete planning’.¹²⁴ Indeed, even when disability services include offering appropriate advice about such legal options, parents may spurn such advice, to the frustration of professionals.¹²⁵

Good practice, then, involves educating legal practitioners about the range of such contextual factors in play. As Cheryl Tilse and her colleagues concluded from their fieldwork, there is:

a need for ongoing education (for legal practitioners) in areas of the law specifically relating to older people Such training should incorporate aspects such as the social and emotional aspects of future planning and decision making, family dynamics and competency. Additionally, lawyers who work in elder law need an understanding of local contact points for referral to services and support networks for older people.¹²⁶

And good practice requires real knowledge of the options available, and how best to utilise them.

C *Financial Abuse and Mismanagement*

A key dimension of the social context of planning for the future is the risk of ‘financial abuse’ – the illegal or improper use of a person’s property or finances – of people with impaired capacity (and their carers) – and/or the adoption of risky financial practices.¹²⁷ Cheryl Tilse and her colleagues have reported research findings that provide evidence of ‘poor accountability procedures, reports from older people of coercion or intergenerational pressure and misuse of EPAs (enduring powers of attorney)’.¹²⁸

There are a number of additional difficulties. For example, some clients cannot nominate an appropriate trustee. They do not have a family member or friend who can assist or who they trust, and they are unwilling to nominate the Public Trustee because of the fees charged or the public ‘reputation’ of that institution for being inflexible, failing to take adequate guidance from the person’s carer and for being more interested in preserving the funds in the trust than providing a reasonable standard of living for the

¹²³ Llewellyn et al, above n 29, 379.

¹²⁴ Bigby and Ozanne, above n 43, 274.

¹²⁵ Llewellyn, above n 64, 146.

¹²⁶ Tilse et al, above n 118, 40.

¹²⁷ A definition adapted from one used by C Tilse, J Wilson and D Setterlund, ‘The Mismanagement of the Assets of Older People: The Concerns and Actions of Aged Care Practitioners in Queensland’ (2003) 22(1) *Australian Journal of Ageing* 9, 9. See also Tilse et al, above n 33, S55.

¹²⁸ Tilse et al, above n 33, S55.

beneficiary. Parents may perceive that funds are not invested wisely and managed well, or that there is inadequate oversight of trustees.

Where private trust arrangements are already in place they may give such wide discretions to trustees that it is impossible to get the trustees to do anything, or be drawn so narrowly that trustees cannot meet the changing circumstances of the client's lives. A great diversity of often unsuitable trust arrangements have been found previously (for example, few leave direct gifts to the person with the intellectual disability, many involved splits of family assets among persons without intellectual disability on an assumption, sometimes unfounded, that siblings of a person with intellectual disability would provide for their sibling). Some trust arrangements appear to be used for tax avoidance purposes rather than to advance the care of the person with impaired competence.

V THE WAY FORWARD?

So what should be done to help people with impaired capacity and their carers realise their human rights when planning for the future?

While older parents or carers with adult children who lack competency are likely to be concerned primarily with planning for the future welfare of their adult child or children, their legal requirements are as varied as anybody else's legal requirements – covering issues such as accommodation, health care, medical / dental consents and service provision.

Ideally, parents and carers should be in a position to make decisions about legal services themselves. This involves raising awareness about services and service users. Many parents have been shown to have become alienated by the present system, so information providers have to make efforts to establish and maintain a greater sense of trust with clients so that they feel they are getting what they want. As we have noted previously:

The system of service provision for people with disabilities can be confusing even to the professionals within it. For families this confusion about what is available and how services can be accessed compounds their existing difficulties. This confusion is in turn compounded by the shortage of services. Planning for the future care of a son or daughter in this context is virtually impossible. While it is clearly not possible to put in place guarantees about future service provision, there is a great need to work in small ways to make the service system more coherent for those seeking accommodation and support.¹²⁹

People with impaired capacity and their carers need access to legal planning and related services which are inexpensive, accessible, informed, independent, reliable and sensitive to their needs. Yet their experiences with services can be confusing, dissatisfying and at times even alienating. To improve the prospects of people receiving well-informed and sensitive advice, it will be necessary to make progress on at least three fronts: (1) the elimination of access problems; (2) the enhancement of referral networks; (3) and the provision of adequate services.

¹²⁹ Eloura Homes Report: Keyzer, Carney and Tait, above n 5, 43.

A *Reducing Problems of Access*

In view of the difficulties which are faced in accessing services, information should be available at every relevant service or institution which may have a connection with people with intellectual disability and their carers including aged services, specialist disability services, medical services, psychiatric services, rehabilitation services and legal services. The common denominator is *need*. However, access points to various services vary. People with intellectual disability and their carers have diverse and varying needs. Improvement of access is critical to ensure that there is sufficient time available to plan for the future so that carers of people with intellectual disability are not left thinking: 'I hope he dies before me'.

B *Strengthening Referral Networks*

It is not necessary for every service or institution to be an expert on legal service planning. Once access has been enhanced along the lines described above, a centrally-located resource and referral network could be set up using common information resources. This could pick up on the expertise of agencies like the disability discrimination legal centres, community legal centres and other interested people who may have the capacity to remove information barriers which occur in professional networks. The information resource could also have an educative function, with key legal materials dealing with issues such as 'parental rights' and concepts such as the 'least restrictive alternative' explained in plain language for the benefit of participating professionals generally.

C *Sensitising Services*

People with intellectual disability and their carers need to feel that there are options available to them that are secure, yet flexible, and which maximise their personal autonomy. People need to feel comfortable with the planning process and be engaged in that process. Often carers can provide the advocacy which is needed to ensure that people get the best plans for the future. However, there is also a need for planning to take place in an environment informed by an awareness of goals such as the least restrictive alternative. In some circumstances there may be a need for monitoring and review of arrangements made to ensure that these goals are achieved. In this context, a graduated response increases the likelihood that review will not be met with resistance. As outlined above, there is a first objective of developing better educational resources, referral networks and other professional tools.

D *Conclusions*

To sum up, our research suggests that there is a distinct need for well-informed and sensitive advice about planning for the future if the human rights of people and their carers are to rise beyond mere rhetoric to become meaningful in practice. This need could be better met if resources are directed to the problems with access to justice we have outlined, particularly toward the strengthening of referral networks across services and toward the sensitising of those services.