VIC
Carers
AUSTRALIA

Senate Community Affairs Reference Committee

Planning options and services for people ageing with a disability

Questions on notice from committee hearing 29/11/10

Q 1: Are the issues which stem from the current laws and mechanisms for Guardianship and Administration shared in other states?

In addressing this question we have defined disability broadly as inclusive of people with physical, intellectual or psychiatric disabilities who also have decision making disabilities. These are the people who are less likely to be able to plan for their own futures; and more likely to have limited assets. They are people whose families may have supported and assisted their decision making for a lifetime. They and their families will be anxious about the future.

Adults with capacity can put in place arrangements for the future management of decisions about their financial, legal, medical and lifestyle issues in the event they loose capacity. They make advance appointments of Enduring Attorneys (financial and medical), Enduring Guardians or Medical or Health Attorneys, depending on the jurisdiction. These take effect when they are no longer in a position to act for themselves. They can also make future or advance directives. Usually such decisions are made in consultation with family and friends. Adults without capacity (i.e. people with 'lifelong' decision making / intellectual disabilities) do not have equal access before the law to making such arrangements in consultation with their families and friends.

Carers Victoria attaches a document developed by Ben Fogarty, Principal Solicitor for the Intellectual Disability Services Rights Service (NSW). It outlines the similarities of current guardianship and administration laws across state and territory jurisdictions, as they relate to people with 'lifelong' decision making disabilities.

From it (and our knowledge of other states and territories) we conclude the following.

- People with life long decision making disabilities and their families have poor access to mechanisms to make anticipatory appointments of substitute or supported decision makers, particularly in relation to financial and legal affairs and lifestyle decisions.
    - The wishes of parents for a person(s) to assist the person with a disability with medical, financial and lifestyle decisions can be expressed in a Will, to be put in place after their death. This is not legally binding for people aged over 18, where the appointment of Guardians or Administrators is the province of Tribunals. Formal appointments are unlikely to be made unless the estate is contested or a guardianship or a protective financial management application is made.
    - Most people with a disability and their families prefer that supported and substitute decision making is undertaken by trusted family members or friends.
    - There is no mechanism which allows parents and people with decision making disabilities to appoint a family member to manage financial, medical or lifestyle decisions when they are frail and old or when they wish to establish in advance a smooth transition to new arrangements for the support of the person with a disability.

- Current approaches to guardianship and administration in all jurisdictions include a protective rather than enabling orientation of the law; a preference for informal arrangements; a focus on the least restrictive alternative and generally on single decision orders by Tribunals. Substitute decision making through formal appointments of Guardians or Administrators is appropriately considered a last resort.

  - While family members may be appointed as financial administrators there are reporting obligations and costs that some consider onerous.
  - Family guardians are rarely appointed except in relation to a single, limited or temporary decision. Return visits to the tribunal by family members can be necessary.
  - Financial administration orders can be frustrating and impersonal for the person with decision making disabilities if the administrator has a poor understanding of their wishes and choices.

- Tribunals which have a protective function may develop a skewed and distrustful view of ordinary families. This results from their work with the complex family conflicts which may be involved in applications for Guardianship or Administration.

- While informal support with decision making is preferred in all states and territories we note that:
  - This approach developed in an era where family support and assistance in the affairs of the person with a disability was rarely challenged.
  - Informal decision making through ‘person responsible’ arrangements in most jurisdictions work well in relation to general health and medical decisions. It works less well when there are lifestyle decisions to be made about post acute care or rehabilitation and there is pressure for early discharge.
  - Informal financial and lifestyle decisions have been impacted on by the introduction of privacy regulations, confidentiality rules, fears about financial abuse and the trend within organisations to become increasingly risk averse. This creates significant barriers for family members to support the decision making of their relative.
  - Caring families in informal support roles have significant difficulties with representing the person with a decision making disability to banks and other financial institutions; in dealing with landlords, utility and insurance companies, Medicare, Centrelink, the Australian Tax Office and in liaising with day and residential service providers. Yet caring families and friends, with some exceptions are usually the most enduring advocates and supporters of people with decision making disabilities.
  - The resolution of informal representation issues <u>may</u> be possible if families produce medical and school reports, or organise an endorsement by a solicitor to the relevant institution to negotiate informal representation arrangements. However, this:
    - Throws the onus repeatedly onto family members. This is not helpful.
    - Does not resolve the issue of constant challenges from within the one institution or between several institutions.
    - Can mean that there is an intergenerational transfer of ‘challenges to informal authority.’ Informal arrangements have no legitimacy.

- Some organisations such as Centrelink offer ‘nominee’ arrangements which respectively authorise ‘a person permitted to inquire’ or ‘a correspondence nominee’ and /or ‘a payment nominee’:
  - These are not recognised by other financial institutions which may require an Enduring Power of Attorney, Financial Administration or Guardianship order.
  - They emphasise proof of relationship but not whether or not the person with a decision making disability has an understanding of the nomination.

- Little assistance is provided to people nominated as decision makers through Enduring Powers of Attorney or Guardianship arrangements or through the ‘person responsible’ mechanisms for medical, dental and health treatment. There is no information or education offered to caring families to build their capacity in the informal role(s) they accept in substitute and supported decision making.

- The absence of a mechanism for families, in collaboration with the person with a disability to put in place a 'succession' arrangement in the form of formal Guardianship and/ or Administration means:
    - There are no formal representation mechanisms available to encourage and formalise future planning discussions between the person with decision making disabilities; their parents and other family members.
    - Informal arrangements fail to provide reassurance that 'the future is in place' for parents and for people with decision making disabilities.
    - There is uncertainty for families and people with a disability as a consequence of the gap between demand and supply of housing and support. Anxiety can be eased by the knowledge that a 'successor' who cares about the person with a disability has accepted an appointment to oversee financial, medical and lifestyle decisions.

- Many people with decision making disabilities could be assisted to appoint future enduring attorneys or guardians (medical, financial and lifestyle) within the mechanisms available in each jurisdiction. They could use shared supported decision making processes with their parents and family.
    - Unlike financial administration, these are accessible and involve no cost. They are commonly based on preferred kinship networks.
    - Where these have been undertaken, we are told they have been challenged on 'capacity' grounds by Tribunals – regardless of the clear preferences and understanding of the person with a disability and their family. Informal supported decision making has no legitimacy.
    - There will be a minority of people with more significant decision making restrictions who require a mechanism for the appointment of an ongoing substitute decision maker.

State and Territory reviews of guardianship and financial administration laws

Both Victorian and NSW governments have announced reviews of guardianship and financial administration arrangements.

In Victoria, the Victorian Law Reform Commission is the process of reviewing guardianship and administration laws and will release a consultation paper in early 2011 with draft reform options for stakeholder consideration. The Consultation Paper will explore how the law can be clarified and improved to better protect the rights of people with disabilities who are unable to make or have difficulty making important decisions. The Commission will present its preliminary views about reform and propose a range of possible reform options for discussion.

The NSW Legislative Council Standing Committee on Social Issues reported 30/6/09, but its report does not consider issues concerning the formalising of mechanisms for supported decision making for people with lifelong disabilities.

What the Senate Community Affairs Reference Committee can do

Guardianship and financial administration laws, together with legislation concerning the appointment of enduring powers of attorney or guardianship (and their equivalents) are the responsibility of state and territory governments. People with 'lifelong' decision making disabilities and their families are minority stakeholders. They are currently very disadvantaged.

There is a need for promotion of the consistent national development of proactive legal mechanisms which:

- Enable people with lifelong decision making disabilities and their caring families and friends to discuss, agree and put in place formal arrangements about the future person/ people who will provide ongoing supported or assisted decision making and guidance for the person with decision making disabilities.
- Provide mechanisms to formalise substitute decision making arrangements according to family preferences, for people with very significant decision making disabilities.

Q 2: Planning for future transitions. How would a register work?

There is a pressing need to develop experience and practice wisdom in the disability sector concerning best practice in transition support for ageing parent carers, their offspring and families. The testing of a comprehensive, well resourced approach to the complex tasks confronting ageing parent carers is needed. Services would actively engage with people with a disability, and their families to develop, implement and support individual and group plans for transition into care outside the family home.

Two key related initiatives are required.

1. A state coordinated and regionally implemented register of ageing parent carers, accompanied by an outreach support service.
2. A ‘planning for future housing’ service.

A register of ageing parent carers and outreach support service

Operating on a state wide basis, and through processes of outreach and relationship building, the register would identify and register ageing parent carers (with their permission) on a centralised database. It would maintain consistent planning data about family needs and circumstances and the needs and circumstances of the person with a disability.

The needs and circumstances of registered families would be regularly monitored and reviewed by allocated key contact workers or case managers - generally people already engaged with ageing parents and their offspring. They would regularly make contact, and as required, negotiate access to and coordinate the delivery of needed and available in home respite and other support services. These would include existing services in the disability sector, new services developed from Government funding initiatives, as well as services from the aged care sector for which ageing parents may be eligible. Coordinated programs of support would aim to maintain care in the family home where that is the preferred option.

Key contact workers would be appointed according to family preference, and by collaborative agreement between regional agencies. They would be named on the register. Their outreach and monitoring work would be guided by a policy framework governing program operation, protocols and procedures, as well as key performance indicators. Their allocation would aim to minimise duplication and overlap between agencies.

Key contact workers would encourage ageing parents, their family and significant others to develop current support plans, emergency care plans, financial plans and longer term plans for future transition. The register would reassure ageing parents that their needs, circumstances and future plans were known to services providers and governments.

A planning for future housing support service

This would be coordinated with the work of the register and outreach support service. It would target and select ageing parent carers with high priority needs for support with the transition of their son or daughter to alternative care. It would actively engage with people with a disability, their peers, their ageing parents and other family members to plan, develop, implement and support planned transitions into care outside the family home over a 3-4 year engagement period. Principles such as individual and family choice, empowerment and supported planning processes would govern program operation.

The project would require:

- A guaranteed commitment of growth funds over 3-4 years;
- Quarantining and pooling funds from the allocations for housing and support and flexible support packages to address the current and future needs of a defined number of participant families;
- The capacity to progressively plan and develop a small range of housing options with appropriate, individualised levels of support for participants;
- Where feasible, exploration of the potential to combine private and public resources to develop:
    - Shared supported accommodation options
    - Shared and mixed equity housing options
    - Private housing arrangements with family managed funding;
- The appointment of a skilled transition support worker/accommodation planner to explore the needs and wishes of the person with a disability and their ageing parent, and explore the resource capacity of local services providers to deliver flexible accommodation options. The transition support worker would work progressively with selected families to collaboratively plan and oversee the development of housing options that are most appropriate to their needs. He/she would broker planned options with local services providers. Extended periods of discussion and planning are likely to be required by some families.

The engagement of participant families in broader processes to plan for the future would be a component of the program. This would include wills, trusts and estate planning, the development of emergency care plans and the strengthening where necessary of ongoing networks of psychosocial support for the person with a disability. The program could include:

- The development of local, accessible, affordable and quality legal and financial advice that is ‘disability sensitive’. There is potential to develop this through regional Community Legal Centres, with workforce development and fee subsidy arrangements as necessary;
- Implementing programs to build psychosocial support for people with a disability who move to alternative care; to encourage the engagement of concerned relatives and friends in the provision of ongoing support of the person with a disability.

Implementing the program

This would require:

- Mapping identified ageing parent carers and gathering, with family permission, data about their needs and circumstances. A computerised across agency mechanism was developed in Victoria in relation to bushfire relief.
- Mapping existing and proposed regional services relevant to the target group;
- Defining available regional growth budgets and their capacity;
- Detailed and collaborative interagency planning of the operation of the program, including the development of regional policy frameworks, and operational guidelines for the register and outreach components, and policy and operational guidelines concerning housing options;
- Capacity building and training for key workers and for key staff in Community Legal Centres.

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