Planning a good life

Futures Planning Framework
Futures planning framework

1. Choose the planning tool that is right for you
2. Develop a plan through a planning service or with a planning facilitator
3. Seek legal and financial advice about wills, guardianships, trusts
4. Arrange informal supports to suit your plan
5. Seek formal supports to suit your plan
Introduction

This framework outlines how people with disability and their families, in the ACT, will have better access to individual planning at key points in their life. The framework outlines current planning supports, research on best practice, barriers to planning as well as new initiatives to be put in place over the next four years.

This framework includes a practical guide to encourage and assist people to undertake more formal planning. The guide is a living document and information about new ways of planning and implementing plans will be updated from time to time.

Where have we come from?

All people with a disability should be able to obtain assistance to plan in advance for life transitions, like leaving school, starting employment, beginning a relationship, leaving home, maturing and growing old (page 12, Challenge 2014).

Not all people write or prepare a formal plan with goals, objectives and timeframes that they (or someone else on their behalf) will review and update. However, most people have a broad idea of where they are heading and what they might need to do to get there. Many people sit down with someone, at different times in their life, and talk about that direction and what they might need to do to get there.

Parents generally think long and hard about the school, training or ongoing education their children may need to reach their goals. Many parents anticipate that they will be supporting their sons or daughters through many of their life transitions and they plan their own lives accordingly.

For people with a disability and/or the families and guardians who care for and protect their interests, preparing for life’s many transitions is important so that they can anticipate a good and fulfilling life, as anyone else might.

Recognising this, strategic direction 2 of Future Directions: A Framework for the ACT 2004–2008, included actions to strengthen the capacity of people with disabilities, their families and carers to take the maximum possible control over their own lives. Objective 2.4 focussed on new services and funding models that supported and encouraged people to take a longer term approach when thinking about and preparing for the future.
Actions under this strategic direction developed policy and provided funding to:

- support a range of family governed and managed arrangements
- deliver futures planning assistance and guidance through formal partnerships with community agencies
- provide training for people to build their natural support networks and use them more effectively
- assist people to implement and review their futures plans
- build the capacity of the ACT business, sports and arts sectors to enable people to achieve their goals of engaging in a wide range of social, recreational, vocational and cultural experiences.

Additional to the work undertaken in the policy and funding arena, Disability ACT has worked closely with the ACT Department of Education and Training to develop a culture that actively engages people in planning and implementing strategies to get the best outcomes as they transition from school to adult life. This has included supporting a range of initiatives that assist people to build their natural supports and decrease the need to solely rely on the formal services.

Where are we going?

*Future Directions: Towards Challenge 2014* aims to build on this work and achievement, over the next four years, and engage more people in planning for their good life.

What is futures planning?

Planning is a way of clarifying our hopes and dreams for the future. Planning can be an intentional, structured process that helps people set clear goals and actions to achieve these goals. It can also be a state of mind that influences everyday thinking.\(^1\)

The literature on futures planning is diverse and reflects a range of thoughts and visions about what futures planning is and should be.

Generally, futures planning is a term used to describe an activity that is undertaken to enable people to make plans for their future. Some people also refer to futures planning as succession or transition planning.

Futures planning centres on creating a vision for the future and exploring how the vision can be achieved.

Futures planning takes into account all of the domains of life that would be considered by anyone thinking about how they might establish a good life for themselves, a person they have guardianship or are caring for, or sharing their life with. For example, future planning may include thinking about:

- early childhood education, school, college and university
- housing
- work, vocational skills training or alternative options for career or vocation
- building social networks
- hobbies and interests
- roles now and into the future including those of being a partner, parent, worker or retiree.

\(^1\) Ward, 2008.
Elements of a futures plan

A futures plan is dynamic and usually covers things like:

- my dreams, aspirations and goals
- who will be in my life and how will I build my community and natural supports
- how will I keep myself safe
- who will assist me to make decisions—big and small
- what do I need to consider in relation to my legal and financial arrangements
- what do I want for my current and future living arrangements including my housing, tenancy and support
- do I want a career, a job or a vocation.

Plans usually cover things already experienced which could happen again as well as things which are expected to arise in the future (for example, life changes or health issues as you age).

Importantly plans should also identify the types of support, whether that be formal or informal, you may need now or into the future. This support may be drawn from family and friends, the local community and specific community groups. It may include government and community services like disability, health and housing services, subsidies and concessions and funding.

Most literature suggests that advice and assistance should be sought to inform elements of futures planning. This relates to the potential complexity of some financial and property arrangements and legal requirements.

Best practice features—what works well?

Some of the key elements of an effective planning culture are:

Promotion

It is important to promote future planning programs and initiatives so that people are more aware of the need to plan for the future and why. Promotion needs to occur before making contact with people or holding information sessions and workshops.

An example of positive action in this area is a toolkit developed to assist service providers to engage carers who were previously unknown to the formal service system, and to facilitate the development of social networks for older carers. Carers NSW and Council on the Ageing (NSW) Inc developed and distributed the toolkit that contains a number of materials to support the engagement of older carers (for more information web search “support coordination of older parent carers”).

Information

Information sessions are a good first step in getting people to think about their future care and living needs. Information sessions present an opportunity for people to meet other people in their local area and expand the range of informal and formal support available for them or their family member.

A number of providers in the ACT have undertaken a series of small group future planning workshops. These are developed as a series of 3–4 one day workshops and include all members of the family. They provide the opportunity for all involved to develop their understanding of the process to develop plans, and strengthen networks with other families and service providers.
Service coordination

A number of government funded future planning programs and initiatives use a coordinator to assist with futures and transition planning. This can be very effective because the worker gets to know the family and how best to work with them to respond to their needs. Some research and our experience confirms the importance of having a long term coordinator to work incrementally with older carers in future planning.

Person-centred approaches

Futures planning is a family issue. Placing the person with disability at the centre of decision-making is imperative to the development of future planning programs and activities.

Effective futures planning takes a person-centred approach that discovers and acts on what is important to the person. It is a process for continual listening and learning, focusing on what is important both now and in the future, and acting on this in alliance with the person’s family and friends.

In particular, the approach seeks to creatively organise supports to achieve meaningful goals, based on the person’s strengths and preferences.

The National Disability Agreement includes a focus on a person-centred approach to service delivery. This includes the person with a disability, their family and carers having choice and control over their own lives and the supports they receive.

Key person succession planning

A model for key person succession planning, in which a person or number of people are nominated to assist the person with disability when their carers are no longer able to, may be a very effective way of ensuring the needs of the person with disability are met (Bigby and Ozanne 1999) into the future.

Key person succession plans centre on the nomination of another person to take over the parental focus on wellbeing. The advantages of this type of planning are that it allows flexibility and responsiveness and identifies a person to oversee primary care and service provision.

These types of plans ensure the continued availability of an informal supporter who can advocate on the person’s behalf and ensure that unexpected changes in their life are dealt with by someone who genuinely has an interest in them (Bigby and Ozanne 1999). An example of this approach is the Planned Individual Networks Model.

Support networks

A number of programs have suggested that a support network, or circle of friends, be developed as part of the planning process.

A support network is a group of people who come together to assist the person and share in their life. This ensures that the person always has others around on whom they can rely to assist them when the need arises.
Access to futures planning advice and services

While some models for futures planning suggest a single access point (Graham, 2009), others believe information should be available at every relevant service or institution that may have contact or connections with people with disability, their families and carers.

Reforms under the National Disability Agreement Service Planning to Simplify Access priority include simplified access to information and services. Access pathways take into account the particular needs of families and carers including older carers and people at different life stage and transition points.

To simplify access and improve pathways, the National Disability Agreement includes a commitment to consider the benefit of single access points.

Futures planning programs and initiatives should be accessible through the various disability access pathways or single access points when they become available. However it is also important for information about futures planning to be available outside the disability service system, especially for older carers and parents of young children who may not be connected with the formal services.

There is limited information available on future planning needs or how to best engage Aboriginal and Torres Strait Islander Australians and people from culturally and linguistically diverse backgrounds in future planning activities. The NSW Department of Ageing, Disability and Home Care has developed a resource *Taking Care of Business: Planning Ahead in Aboriginal and Torres Strait Communities* — to assist people in Aboriginal and Torres Strait Islander communities to plan ahead and prepare for times when they can no longer make decisions for themselves (Moore 2008).

What gets in the way of futures planning?

Some of the reasons why people don’t engage in futures planning include:

**Futures planning is challenging:**

- Futures planning may be perceived as being emotionally draining and challenging as it forces people to face their own mortality and address difficult psychological, ethical and practical issues.
- Some people focus on the here and now and may not have time or capacity to search for assistance with future planning.
- When planning for the future, people may need to discuss issues that are sensitive and/or private like the value of assets and unspoken assumptions about other family members.
- Some carers may see their role as being family business, which should not be discussed or supported outside of the family.
- Research has also indicated that some people do not want to do something they perceive may result in the loss of control or responsibility for themselves; or in the case of a carer, they do not want to lose the control for the person they care for. In planning for the future, they realise that they will one day lose that control and potentially lose their sense of self and purpose.
Lack of information and assistance to address legal and financial issues:
- Some researchers report that there is a significant unmet need for legal service practitioners who have an understanding of the needs of people with disability, their carers and families. The researchers also indicated that people are generally poorly informed about planning tools such as the Enduring Power of Attorney.\(^2\)
- A further concern people may face is a realisation that they may not have the financial capacity to cover the cost of future care and/or support arrangements and the cost of the assistance to prepare future plans. It has been recommended to government that no or low-cost legal and financial advice be made available for carers to assist them to obtain necessary financial and legal advice.\(^3\)

Limited access to funded solutions:
- In a prioritised funding environment, many services may not be readily available for example, supported accommodation. Some people may believe that there is no point planning for the future when there are limited resources available and/or what they see as an ideal future depends on significant resources being available.
- Some people express concern that formal services cannot deliver the same quality of support and protection as their family does.

Fragmented service provision:
- Some people feel that formal services are fragmented and they don’t know where to get assistance and information about planning. Some service providers and researchers also agree that the service system is fragmented and/or inadequate and that it is difficult for people to get assistance with planning for the future.\(^4\)
- Researchers have found that some people feel that service providers do not understand their needs, issues and concerns.\(^5\)

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\(^2\) Carney and Keyzer 2007a; 2007b; Keyser and Carney 2009
\(^3\) Senate Standing Committee on Community Affairs, 2008
\(^4\) Bigby 1996; Pearce and Bigby 2007
\(^5\) Llewellyn et al 2003
What will happen over the next four years?

Disability ACT is always looking to improve the availability and quality of planning assistance for people with disability and their families. Some of the initiatives we are working on to be available over the next four years are:

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<tr>
<th>WHAT</th>
<th>WHO</th>
<th>BY WHEN</th>
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<tr>
<td>Maintain and update a <strong>Good Life Planning Guide</strong>. This guide will be promoted through disability specific and universal community groups, newsletters and directories. The guide will be maintained in electronic and printed form.</td>
<td>Disability ACT</td>
<td>2011</td>
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<td>An annual calendar of information sessions will be held by House with No Steps Transition Service about the range of planning and post school options and supports delivered.</td>
<td>House With No Steps</td>
<td>2011</td>
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<td>Introduce <strong>Good Life Planning Grants</strong> to enhance access to planning facilitators, workshops and coordinators who can help create family governed services.</td>
<td>Disability ACT</td>
<td>2011</td>
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<td>Work with its funded providers to enhance the availability and quality of individual planning tools.</td>
<td>Disability ACT</td>
<td>2014</td>
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<td>Recruit for a new role of <strong>Housing Options Coordinator</strong> to work alongside and assist people to develop their future housing, tenancy and support options.</td>
<td>Disability ACT</td>
<td>2011</td>
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<td>Introduce a <strong>Personal Outcome Measures Tool</strong> for people who are residents of the Disability ACT Accommodation Support Services or supported by its respite and children and young people services. The tool, developed by the Council on Quality and Leadership, takes a person-centred planning approach that discovers and acts on what is important to a person.</td>
<td>Disability ACT</td>
<td>2011</td>
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<td>Introduce a ‘<strong>no wrong doors</strong>’ approach in which first contact community and government agencies take responsibility to assist people to navigate the service system.</td>
<td>Disability ACT</td>
<td>2014</td>
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<td>Streamline the provision of personal information which is collected from people applying for government and community support and/or funding by:</td>
<td>Disability ACT</td>
<td>2014</td>
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<td>- Establishing a common personal information collection tool</td>
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<td>- Investigating a central portal to streamline access to information, support and accommodation services</td>
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<td>- Harmonising eligibility and assessment requirements</td>
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<td>- Making a range of case coordination models available.</td>
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Further information about new planning developments will be available from:
- disability.sgg@act.gov.au
- (02) 6207 7481
# Glossary of terms

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<tr>
<th>Term</th>
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<tr>
<td><strong>Disability</strong></td>
<td>To be eligible for formal disability support services funded by the ACT Government you must have a disability that is attributable to an intellectual, cognitive, neurological, sensory or physical impairment, or a combination of these impairments. The person with a disability will need support due to a substantive reduction to their capacity for communication, social interaction, learning or mobility. The disability is permanent or likely to be permanent and may be of a chronic episodic nature. For the purpose of the Good Life Planning Grants priority will be given to people with a disability who: ■ are under 65 years of age, and ■ have a primary disability that is not solely attributed to a mental illness.</td>
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<td><strong>ACT residency</strong></td>
<td>You must be living in the ACT for a period of six months and can verify residency upon request by producing utility notices, lease agreement, mortgage papers or other such documents which support residency for the specified period. Interruptions to ACT residency of six months and not in excess of 24 months shall be considered as meeting residency criterion provided that: ■ the applicant can clearly establish that the ACT remains his/her permanent place of residence ■ the absence is due to the necessity to access rehabilitation or specific supports not available in the ACT and supporting documentation is available on request.</td>
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<td><strong>Improving community access</strong></td>
<td>Describes goods and services that assist you to travel to, and access the ordinary places in our community. The aim is to support the shared use of ordinary settings.</td>
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<td><strong>Improving community participation</strong></td>
<td>Describes goods and services that improve your network of relationships. This includes relationships with immediate and extended family members, close and casual friends, work colleagues, broad acquaintances and intimate relationships. The aim is to protect and enhance the relationships people currently have, and to assist people to develop new relationships and networks.</td>
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<tr>
<td><strong>Increasing skills and abilities</strong></td>
<td>Describes goods and services that assist you to function and perform better in your day-to-day life. This may involve developing new skills, improving existing skills, or improving confidence or self esteem.</td>
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<td><strong>Improving choices</strong></td>
<td>Describes supports which improve your autonomy in decision making: from small every day decisions to major life-defining matters. The aim is to organise the necessary support to increase your control over your life.</td>
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<tr>
<td><strong>Improving personal respect</strong></td>
<td>Describes supports which act to improve your experience of having a valued place among a network of people, and of having roles that are valued by other people in our community.</td>
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<td><strong>Strengthening family and carers capacity</strong></td>
<td>Describes supports which improve the capacity of family, friends, and unpaid community members to assist you. The aim is to assist these relationships to remain strong and positive.</td>
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<tr>
<td><strong>Addressing imminent risk to health and safety</strong></td>
<td>Describes supports that will reduce the likelihood or occurrence of any threats to your wellbeing, health and safety, or that of other people involved in your life. The risks are currently present or likely to occur within the next 12 months.</td>
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**What is family governance?**

Family governance is derived from Social Role Valorisation (SRV) approaches, and enables people to create highly personalised and inclusive lives. Family governance is about families taking control of all the influences that impact on the life of the person who has a disability.

This is done by understanding the importance of your natural strengths as a family and how to use these strengths. It is important to know what you would like to achieve with and on behalf of the person with disability, by being clear about your goals and intentions.

Family governance takes time and commitment, you will need to plan, problem solve, be creative and prepared to be flexible if things don’t go exactly as expected.

Some families choose to form a partnership with a community organisation who agrees to ‘host’ their support. Under a hosted arrangement the community organisation and the family come to an agreement on what sort of support the family requires. For example, families may wish to control who is employed to support the individual with disability but may not want the responsibility of controlling the administrative matters such as insurances, superannuation etc. and leave these matters to the host agency.

Families may also choose to pool their resources to create and implement a joint family governed approach. In some cases a coordinator is employed by the family governed group to assist with the general running and planning of the group.

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**What is a family governed service?**

A family governed service is one where people work together using available resources and supports to create the best possible life opportunities for a family member with disability. In some circumstances a small number of families choose to pool their resources to create and implement a joint family governed service plan.

Family governed arrangements offer a high level of control over the type and nature of the services used, and enable families to create services that are more in tune with their culture and lifestyle.

Disability ACT supports a number of family governance arrangements. If you would like to find out about these arrangements, or be put in touch with a family governance coordinator, please contact your Local Area Coordinator, your formal disability support service provider or Disability ACT’s Information Service on 6207 1086.

**Further reading on family governance arrangements:**

- Getting a Life (ACT) — www.gettingalife.com.au
- Stepping Stones for Life (ACT) — http://stmargh.unitingchurch.org.au
- One by one — www.onebyone.org.au
- Planned Individual Networks — www.pin.org.au
- Safeguards Summit 2005 Papers. Individual Governance
- Ten Guidelines for Family Governance
- www.cru.org.au
The ACT Government is committed to making its information, services, events and venues, accessible to as many people as possible.

- If you have difficulty reading a standard printed document and would like to receive this publication in an alternative format—such as large print or audio—please telephone (02) 6205 0619.

- If English is not your first language and you require the translating and interpreting service—please telephone 131 450.

- If you are deaf or hearing impaired and require the TTY typewriter service—please telephone (02) 6205 0888.