



JacksonRyan Partners

**Submission to the Federal
Senate Community Affairs
References Committee**

**Access to planning options and
services for people with a
disability**

27 May 2010

Access to planning options and services for people with a disability

JacksonRyan Partners is a boutique business unit of Max Jackson and Associates. The business activities of this unit focus in particular on disability, public policy and workplace issues.

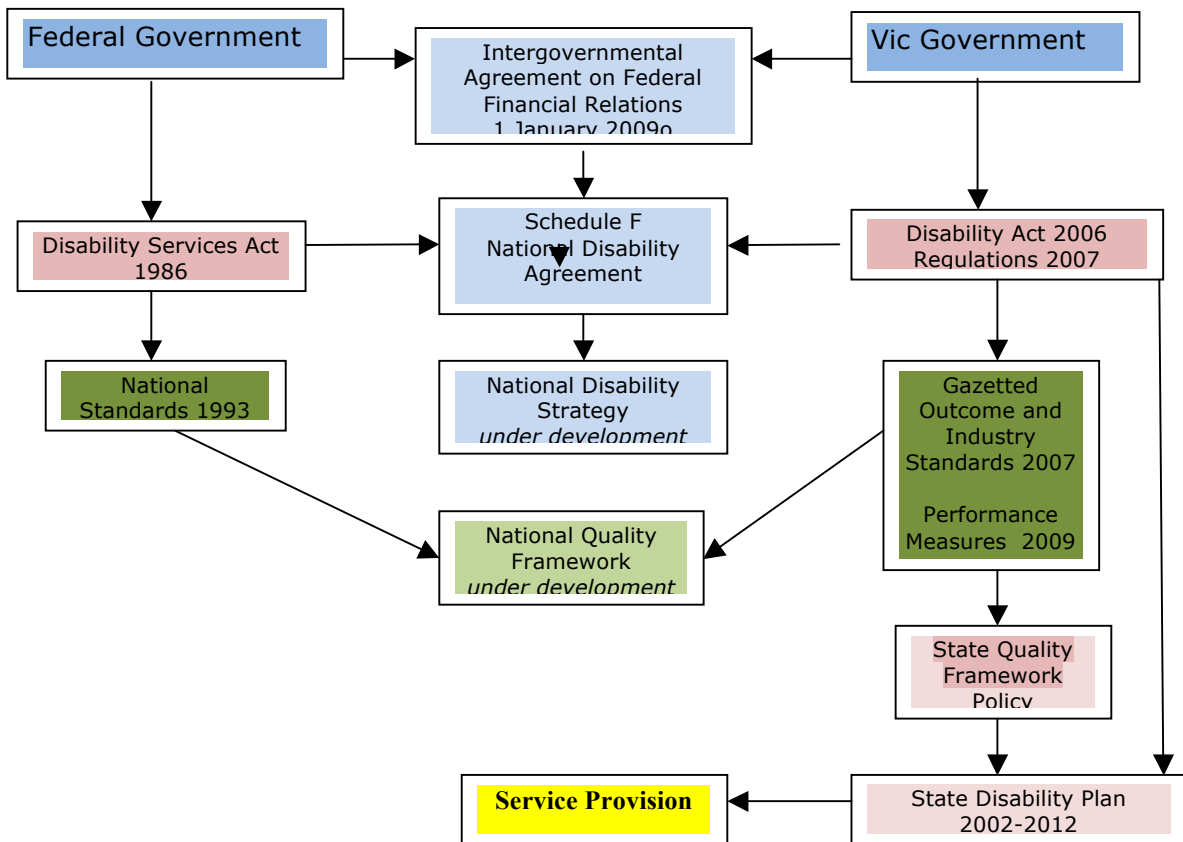
JacksonRyan Partners welcomes the opportunity to make a submission to the Federal Senate Community Affairs References Committee inquiry into *Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.*

To inform the Committee's inquiry, this submission focuses on the situation in Victoria .

Current situation in Victoria

This schematic shows the Federal and State governments' main legislation and agreements which are the basis for service provision in Victoria via the Disability Services Division in the Department of Human Services (DHS).

Federal and State Government Legislative and Agreement Linkages



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It must be noted that under the April 2010 National Health and Hospitals Network Agreement, Victoria is not part of its *HACC and related programs agreement* that the Commonwealth would take responsibility for people aged 65 or more and the State for those under 65. The status quo will remain in Victoria. In information which has been provided by the government at budget estimates hearings, it is apparent that the Victorian government is confused. The changes to funding, responsibility and accountability do not have to mean changes to service delivery which are detrimental to the service user. The costs and benefits of Victoria not being part of the reforms to streamline the service system are yet to be made public.

The right to assistance with planning

Victoria's Disability Act 2006 (the Act) legislates a right to assistance with planning. Section 53. Planning of the Act states *(1) A person with a disability or a person on their behalf may request the disability service provider to provide assistance with planning. (2) The disability service provider must within a reasonable period of receiving the request for assistance with planning arrange for the assistance to be provided.*

The Act at the end of section 52 contains the note: *Planning encompasses a range of responses from a brief discussion and agreement about actions required through to an extensive process and the development of a plan across a whole range of life areas documented in a format that is meaningful to the person and their network.*

The tricky part in this legislation is the wording 'arrange for the assistance to be provided'. This does not mean that a planning service will actually be provided and the planning done within a reasonable period. It means that within a reasonable time that arrangements will be made for the assistance to be provided.

This right to assistance with planning is not well-known or well-understood in Victoria. It can be and is confused with the planning which must take place when a person is getting an on-going service, when the legislation requires that there be a support plan (section 54, Support plan).

Criteria to enable priority of access to disability services to be determined in a fair manner

The Victorian legislation in section 8(2)(d) gives the Secretary of DHS the function to develop and publish criteria to enable priority of access to disability services to be determined in a fair manner.

The Access Policy which has been developed is more effective in excluding people from the funded service system than determining priority in a fair manner, as required by the legislation. JacksonRyan Partners have made a detailed critique of

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this policy in its paper, *Unfair Exclusion: The Outcome of Victoria's Disability Services Access Policy*. This paper, a separate submission to this inquiry, analyses the DHS Access Policy in the context of the reforms taking place in the provision of disability services. The implications of the policy for the availability of service options and choice are also addressed.

It is worth noting here that, as is set down in this paper, *the notion that one person's needs and circumstances are of a higher priority than others sends two signals. The first, assessed needs are not about the individual and his or her right to receive a funded service, but are simply used as a basis for a subjective comparative analysis. The second, the system operates as a crisis response. Therefore, given that identified needs are not met at the time they are identified, then the system will always be crisis driven, because needs not met now will become a crisis in the future - unless of course the person dies before this point is reached.* (p 4).

Four policy rules

The service system in Victoria is determined by four policy rules

- Access
- Planning
- The Waiting List (disability support register)
- Funding, particularly Individual Support Packages

The critical element in each of these is the plan. Disability services are provided

- In response to needs identified in a plan
- To address identified needs of a person
- When other possibilities have been exhausted
- To enable community participation

Support Your Way

The recently introduced theoretical model for Victoria's service system is *Support Your Way, A Self-Directed Approach for Victorians with a disability*.

There are three elements to this self-directed approach:

- Self-directed planning
- Self-directed funding
- Self-directed support

This self-directed approach envisages service providers as helping people to:

- Exercise choice and control
- Self-assess their needs
- Plan for their future in a way that recognises their lifestyle and culture
- Assemble supports from a variety of sources

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- Draw together formal, informal, voluntary and private sector providers

The Department provides an overview of self-directed approach and its perceived benefits – transparent funding, capacity building, flexible service provision, quality improvement, workforce redesign – in the diagram below.

The DHS Self-Directed Approach



Individual funding

In putting the self-directed individual support policy into practice, DHS has developed an individual funding model, whereby an individual receives funding via an Individual Support Package (ISP).

The ISP funding is 'attached' to an individual and is portable i.e. the funding moves with the individual, so if the individual moves from service provider A to service provider B, service provider A 'loses' funding and service provider B 'gains' funding.

The individual can choose how the funding is directed:

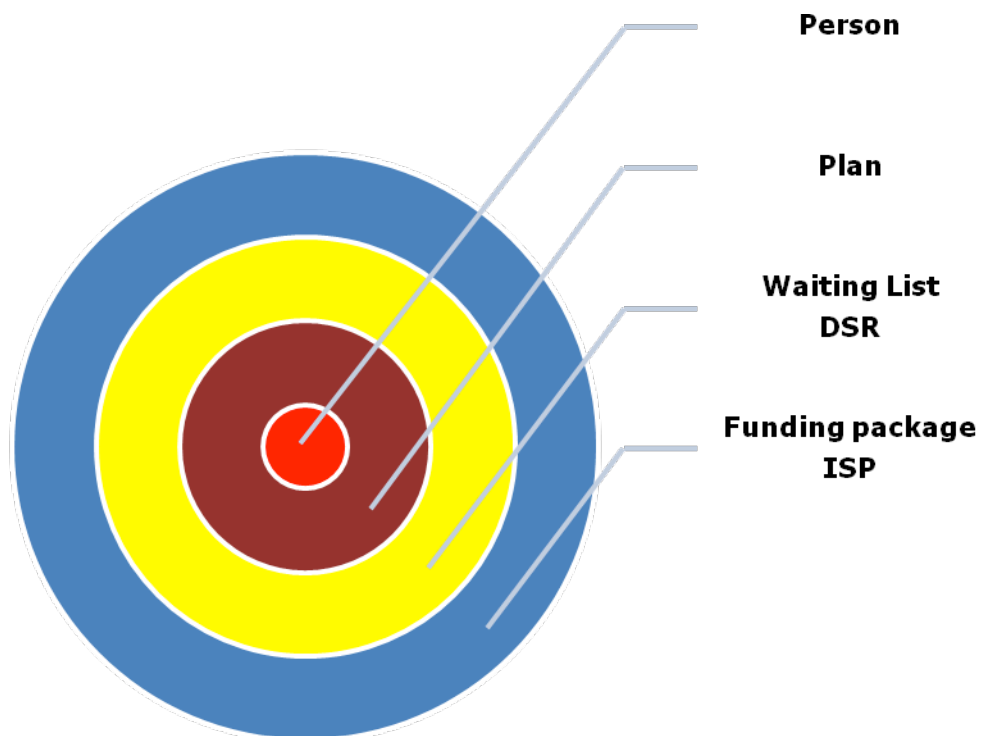
- Direct to the individual, who pays the bills (not yet available to everyone)
- Via a financial intermediary, who pays the bills
- To a service provider, no bills to pay

To get funding via an Individual Support Package, the person must have a plan and go through the Disability Support Register selection process. There is no guarantee that the funds allocated via a package will meet the needs identified in a person's

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plan. Further, if there are changes to a person's needs which cannot be met within a support package, the person must make an application to go on the Register to have these 'new' needs met. A critical element of the waiting list is that it is only for current needs.

Getting to a Funding Package



DHS funding

DHS has developed a unit cost funding model for each activity it funds. However, the case has been made for an upwards price adjustment i.e. DHS is not funding the full cost of service delivery. (Source: Price Waterhouse Cooper March 2009 Cost Report)

Also, there is a sense that DHS is reluctant to fund costs associated with, for example, capital works, transport, compliance, infrastructure, co-ordination, staff vacancies, OH&S and WorkCover, quality.

DHS is moving away from block funding service providers. A driver for not block funding seems to be the assumptions that individualised support cannot be provided when a service is block funded, or, that individualised support can only be provided via individual funding. While these assumptions are open to challenge, this debate has not been, and is not being, publicly held. DHS is moving towards a 'one size fits all' individual funding model.

Emerging problems with DHS focus

There are a number of problems emerging with the way the system is evolving. For example:

- There is not enough funding for individual support, with around 1300 people on the waiting list (Disability Support Register) for support to live in the community or day activities i.e. not looking for accommodation
- There is not enough funding for accommodation, with a waiting list of around 1300 individuals for supported accommodation
- Before funding is allocated in an individual support package, other avenues of funding and support must have been exhausted
- Almost half of the Disability Services budget (\$628 million of \$1370 million for 2010-11) is for residential accommodation services for around 5000 people, which distorts discussion about the funding available to people who do not yet want residential services
- The move is from a 'one size fits all' block funding model to a 'one size fits all' individual support package model, so there is no choice as to whether a person might prefer to access a funded service rather than have funding
- The unit cost does not reflect the full cost of service provision
- The individual funding model cost-shifts to families

More problems are likely to emerge, particularly if a person's needs change and they need more support. The government of Victoria has the strategy of diverting attention away from the needs of people with disabilities and their families by talking about the increased funding it has provided in the past 10 years. However, doubling of funding has not meant double the number of services. Also, in the respite area it is obvious that while increased funding has resulted in increased numbers of people getting a service, there has been a decrease in the average quantity of service a person has access to.

Planning

The real challenge which has not been addressed is how planning assists in meeting the needs of the person with disabilities and their families, particularly when planning results in people languishing on waiting lists. It appears that making a plan or being on a waiting list has taken on the mantle of being a service.

There are of course resources available, such as the 160 page Victorian publication, **Help for Carers: Information for Older Carers & Families of People with a Disability**, available from Carers Victoria and DHS. There is also *Planning for the*

Future People with disability which was published in 2007 by the Department of Families, Community Services and Indigenous Affairs.

The booklet is divided into five sections:

Section 1: Future planning: things to consider helps families to think through some of the issues to consider when planning for the future of their family member with high support needs and encourages families to take a 'whole of life' approach to planning.

Section 2: Planning for the future: choosing the right option talks about the options available to families when planning for the future and is written in a question and answer format to assist you to find information relevant to your needs.

Section 3: Setting up a trust examines how to set up a trust to provide for a family member with high support needs and contains questions and answers about trusts.

Section 4: How to access legal and financial advice gives advice on how to access legal and financial advice and includes information sheets to provide lawyers and financial advisers with information they may need to best advise you.

Section 5: Useful contacts provides contacts in each state and territory, and gives some suggestions for further reading.

Section 6: Planning templates provides a care plan checklist for you to complete with your family, and an information pro forma to complete and provide to your lawyer.

From these section headings, one can begin to appreciate that this is onerous work.

There is also the January 2007 N-Carda Group *Succession Planning for Carers-Report on consultations* which details what confronts families planning for the support of their loved one with disability. As is set out in the report,

*Many respondents indicated that planning for the future is a very difficult proposition for many families and carers. The key **barriers to planning** included:*

- *Families don't know where to start; who to go to; where to find information or what to do.*
- *The costs of disability and caring are such that many parents may not have accumulated many assets in their lifetime and may not be able to financially provide for their child's future, without significant government assistance.*
- *Future planning is a sensitive issue, challenging family assumptions and requiring people to face their own mortality and discuss personal issues and information.*

- *A planned transition is not considered feasible whilst services and governments continue to place only those people with disabilities in crisis or emergency situations.*
- *Many carers are too busy or tired from day to day responsibilities to be able to find the energy to undertake the complex and time-consuming task of planning for the future.*
- *Many ageing carers may not have expected their son or daughter to outlive them and may have unrealistic expectations around what governments, services and family members can provide when they need to relinquish care.*
- *Future planning is an extremely complex issue, across state, territory and Commonwealth law and regulations covering financial, legal, property, taxation and government support issues. Circumstances will change between any plan and its implementation, and establishing support networks is hard work.*

There is also the **Family Relationship Service for Carers** service which, according to their brochures, can provide support and expert advice to help develop a plan for the future care of a son or daughter, ensuring continuity of care and providing peace of mind to the carer and their family. The Federal Government has provided \$9 million over the four years to 2013-14 to continue the Family Relationship Service for Carers Program. This has a service provider in each State and Territory, and in Victoria it is provided via Eastern Access Community Health in Ringwood. It has a website www.each.com.au/en/services/family_relationship_service_for_carers.

Around October 2009 a tender was called for Evaluation of the Family Relationship Services for Carers Program, to identify the efficiency, effectiveness and appropriateness of this program and its ongoing need and value for money. The results of this evaluation do not appear to be publicly available as of now. This evaluation could provide useful information as to how well this service meets the needs of carers.

There is also available the 2009 Allen Consulting Group Report *International Review of future Planning Options*, which was provided to FaHCSIA to identify and analyse international approaches to encouraging private financial provision and supporting future planning by families caring for a family member with disability. One of the more telling considerations of this report is

More careful planning for adults with special needs requires joining their carers with social programs for sustained and effective advocacy in political and judicial arenas... carers cannot be expected to engage in the planning process unless professionals and society more broadly engage in planning for the care of its disabled population. (p 5)

Carers quality of life

There are recent academic studies on the poor quality of life of carers, particularly the 2008 Australian Institute of Family Studies research report No 16, *The nature and impact of caring for family members with a disability in Australia* and the Prof Robert Cummins research work on quality of life. More poignant and more to the point perhaps is the inspired writing of a parent at the end of her tether:

The Seven Habits of Highly Irritated Carers

1. Learn as much as possible about your child's illness/disability, because you are going to be spending the rest of your life arguing with doctors who treat you like a moron because you are just the kid's mother, so what would you know? When your child goes to hospital, you are going to be sitting by his/her bedside all day and trying to sleep in a plastic chair all night, because apparently no one in a general hospital has ever seen a severely disabled person before, and so many staff, you will find, are going to treat your child like some sort of green-tinged Martian. So it's never too early to start boning up on those medical textbooks. As you will almost certainly be administering your child's medication every day until either you or your child dies, understanding medication use can also often be surprisingly helpful. Learn to self-medicate as well.
2. Share the care with family, friends and community services, or at least try extremely hard to. When family, friends and community services tell you to rack off, try Valium, anti-depressants and gin, although preferably not simultaneously. Caring is often more than a one-person job. In fact, in many cases it's a job for about six people, working in three shifts around the clock every day, seven days a week. However, chances are the other five will never turn up. But do try not to wear yourself into the ground, because that would be very silly. Aim for at least three hours sleep a night. Research has shown that the carers who feel most in control of their caring situation are those who drop in for a cuppa and a chat with their ageing mum for an hour each morning, on their way to the gym or the beach.
3. Look after your own physical and mental health if you have a severely disabled child, because you are going to be doing this for a loooooooooooooong time. If you do feel you are about to drop dead from stress, try to have at least one of your other children groomed and on standby to take over your role. If this other child is under 12 years old, let Carers Australia know so they can give him or her a medal and a huge pat on the back. When you look in the mirror, try to remember you are human. Try to get regular rest, exercise and eat healthy meals, because it can be a little demanding being a 90-year-old carer of a 65-year-old son or daughter unless you are in peak physical condition. Take time out to relax if necessary. Research has shown that at least 25 minutes once a year is essential. Apply for respite for regular breaks, and then practise being extremely patient. Research has shown that carers who practice deep meditation and Zen Buddhism live far longer than those who don't.
4. Get as much information as you can on all the types of assistance available, then file it in your garage. Try not to spend your \$50 a week carer's allowance all at once. Save it for special little treats like paying the electricity bill, or perhaps a bit of extra

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food. Because you're worth it! When contacting the schemes that provide equipment etc, try not to pull too much of your remaining hair out, because you already almost certainly look a bit weird. Try to remember from time to time how it once felt like to be human, and make sure you have a holiday at least once every 20 years.

5. Attend to your emotions and talk to professionals if necessary, because professionals just love talking. It is normal for carers to feel any or all of: anger, guilt, frustration, sadness, grief, fear, worry and hurt. In fact, it's so normal, Carers Australia gets \$32 million a year to reassure you it's normal. You are not alone in these feelings. Here at Carers Australia, we feel your pain. Sitting around listening to other carers talk about the desperateness of their situation can often cheer you up no end, and can be a good alternative to running a hot bath and slitting your wrists. If you want to change something about your caring situation, talking to a counsellor may help you sort out your options. Or maybe it won't. But you must have at least five spare minutes every week, so use that time wisely by listening to a counsellor talk meaningless platitudes.
6. Be assertive. Find a railway bridge, stand under it until a train passes overhead and then scream at the top of your lungs. If you need help, don't be afraid to ask. You probably won't get any, but don't be afraid to ask. Also, make sure the doctor/s involved know how caring is impacting upon you, because after all, you are going to need somebody to prescribe your Valium and anti-depressants. The gin you can buy yourself by being assertive with the staff of your nearest bottleshop.
7. Plan for the future. Don't wait until the last minute to organise what to do with wills, power of attorney, guardianship or residential care. Plan ahead for personal, health and lifestyle decisions into the future by obtaining a copy of the Planning Ahead Kit. Then go to the nearest police station or hospital, abandon your disabled child there.

Conclusion

There is no adequate systematic or logical provision of planning options and services for people with a disability to ensure their continued quality of life as they and their carers age. This means that the choice and funding of planning options currently available is full of inadequacies.

It is to be hoped that the current Productivity Commission inquiry into disability long-term care and support will address these inadequacies.

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Suggested citation for this report:

JacksonRyan Partners 2010, *Access to planning options and services for people with a disability*, Melbourne.

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