



*Creating a positive future
for people with a disability and their families*

Submission
to
**Productivity
Commission**
Disability Care and Support

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Preface

On his election, our Prime Minister, Mr Kevin Rudd, promised to be “a Prime Minister for all Australians”. All Australians include the one-in-five Australians who have a disability and their families. Yet, the National Disability Strategy’s 2009 “Shut Out” Report¹ found Australians with a disability are among our nation’s forgotten people *and* “*many... believe disability is someone else’s problem*”.

Blue Skies is a focused network of people connected by their commitment to a compelling vision for change – a vision for an inclusive community. The Blue Skies Scenario calls for an alternate future for people with a disability and their families in Queensland and Australia — a future where inclusion of people with a disability is the responsibility of everybody and to the benefit of everybody.

It envisages a community that is strong and vibrant and embraces diversity. The work to build a strong community is never complete. Wherever a person with a disability lives, whatever their choice of lifestyle, their experience should be one of rich inclusion and with a sense of belonging. The gifts, talents and contributions of ALL citizens are called upon, and in so doing, help build better communities.

For people with a disability, their acknowledged inherent rights as citizens are central to a better life. Emphasis is placed on the right to a secure home and enduring relationships, with service, family and community working well together to provide supports as and when required, in their community of choice².

The notion of a national a disability insurance scheme is a natural outcome of the Blue Skies Scenario, if it provides:

- an entitlement to **timely and appropriate support** to people with a disability
- **increased empowerment** to people with a disability and protects their citizen rights
- capacity for people with a disability to **contribute to society through valued roles** in work, leisure, creativity and spirituality in the communities of their choice
- opportunities to **maintain and strengthen meaningful relationships** with families and enduring friends.

The Blue Skies Team

¹ National People with Disabilities and Carers Council 2009 *SHUT OUT: The Experience of People with Disabilities and their Families in Australia* Canberra

² Blue Skies Team *Blue Skies Scenario* 2009 <http://www.blue-skies.info/scenario> Brisbane

Executive Summary

A new framework for Disability Care and Support must provide support for people with disability in a way that is an entitlement, which acknowledges people's citizenship and a right to participate in society. It focuses on developing their abilities, allows for decision-making by or as close as possible to the person with a disability and respects their natural networks of support, particularly their families and enduring friends.

A new framework does not replace generic services, such as housing, education, transport and health care. Rather, it assists people with a disability to use those services like any other Australian.

Any funding for support would be portable anywhere in Australia, flexible in how it is spent, at all times centred on the needs of the person with a disability.

A new framework will require fresh thinking; it would consist of five key features, all of which, when working well together, will avoid a "blow-out" of costs and work towards a fair and effective service system. They are:

- a specialised service system
- capacity building strategy to assist communities to include people with a disability and welcome their participation
- capacity building of people with a disability to envision what is possible, to plan for the future and to build a good life for themselves
- capacity for research and development to identify the way forward as society changes
- safeguarding strategies, including independent advocacy, administrative appeals mechanism and simple transparent accountability measures for both services and users.

In summary, the scheme would allow people with disability to design and direct their service, so that they receive the right amount of service with the right equipment, by the right people, in the right way and at the right time.

Terminology

When using the term “**people with a disability**” in this submission, the Blue Skies team mean both:

- the adult, with the assistance of those with authority to make decisions for them if they do not have capacity, typically a family member, spouse or enduring friend
- The child with, typically, parents making decisions on their behalf.

The support needs of families and enduring friends should be considered as distinct and separate to that of any decision-making for the person with a disability.

What should a new system aspire to achieve?

Blue Skies believes that any new system should be directed by a set of goals, including:

1. Adequate support to live an ordinary life as **an entitlement** as an Australian citizen
2. An **equitable response** across Australia
3. Response to **local and cultural differences, including rural and remote communities.**
4. **Focus on building on people's abilities** rather than managing their deficits
5. **Social inclusion and participation** of people with a disability as with any other citizen of Australia
6. The **empowerment of people with a disability to direct their lives** and to reach their full potential through their endeavours in work, leisure, creativity and spiritual development
7. **Timely investment in people with disabilities and their families** to maximise personal development, inclusion and skills, avoid further impairment, and maintain natural networks of support.

The system would provide for support for people with a disability in order that they have a "good life", that is, people with a disability would be supported to:

- **envision a worthwhile life** that is inclusive, purposeful and fulfilled
- **plan for the future** and to build connections and opportunities for themselves
- **perform daily living activities** to optimise personal dignity, health, social participation and inclusion
- **identify, build and maintain informal networks of support**, to remain part of a family network, make helpful community connections and find and keep friendships
- **contribute to society** through work, leisure, creativity and spiritual activities.

The system would work collaboratively with generic services so that people with a disability:

- have access to **inclusive education**
- receive **appropriate medical and dental care**, including early intervention to minimise avoidable medical and disabling conditions
- can have secure, affordable and appropriate **housing** in their established communities
- can use affordable and accessible **transport**.

It is therefore critical that any system for Disability Care and Support is coherent with a comprehensive **National Disability Strategy**. If this does not happen, disability support funding will be required to make up for the deficits in the generic community services and opportunities that are available to others.

Funds for support are best used within a **strengths-based model**, that is, a focus on positive solutions rather than measuring deficits. This can best happen when there is a positive vision for the person, a plan and people who will be there in the long term to help build a good life for the person with a disability. The new system will work best if:

- The planning is done by the person with a disability, or if required, people closest to the person and who are likely to be there in the long term
- The paid supports are used to complement and help build the informal supports that already exist (rather than disaffect them)
- People with a disability and/or their families can have as much autonomy in the management of the service as they can manage (this right would be balanced with responsibilities of using the funds towards the best interests of the person and accounting for expenditure).

It is not only people with a disability and their families who benefit directly through a strengths-based model, but also communities, by way of increased citizenship with the responsibilities and opportunities that come with it. Communities do best when ALL citizens are able to share their gifts, talents and contributions.

Similarly, when people are supported in the right way, by the right people, at the right time, they will lessen the demands on other services, such as:

- justice and corrective systems, through avoidable law infringements and incarceration
- health services, through avoidable illness and hospital stays
- child safety services, through the breakdown of natural families and networks
- institutional care, through the breakdown of formal and informal supports within their community.

Who should be eligible?

Who should be in the new scheme and how could they be practically and reliably identified?

Fairness:	The scheme should be an entitlement, that is, available to all people who have a disability who require support.
Timeliness	The scheme should meet the needs of people with a disability: <ul style="list-style-type: none">• who require support with daily living needs• who would benefit from early intervention and development• who are experiencing a time-limited crisis or an emergency situation.
Equity	The scheme should offer equitable access and level of support across Australia.

Which groups are most in need of additional support and help?

This scheme should be available to all people. The people currently in greatest need are people whose disability is ongoing and who are not currently eligible for compensation.

People with mental illness or an intellectual disability are commonly excluded by society's lack of understanding. People whose disability is not necessarily readily apparent face additional social barriers and exclusion, based on ignorance, fear and prejudice.

Given the complex nature of this situation, additional support is needed for individuals to recognise their strengths and capacities, envision a good life for themselves, manage the societal barriers and integrate those strengths into a fulfilling lifestyle, encompassing work, physical, recreational, spiritual and social aspects.

What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

The scheme should not be means-tested. The scheme should offer assistance to allow all people with a disability to live with dignity and participate to a level as are the rest of the Australian population.

People with a disability should not have to fund the additional costs of living with a disability. This should be supported and funded by government.

Who gets the power?

How could people with disabilities have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

Many services have worked towards self-determination for people with a disability and their families regarding the service they receive. Successful services have found the following elements are important:

Transparency	People with a disability know how much money there is for support and how it is being spent.
Ability to plan and decide on the quality and level of support	People with a disability decide how and when and what support should be provided.
Ability to “hire and fire”.	People with a disability decide who supports them and can have them dismissed if they no longer provide the support required.
Ability to change the service provider without question.	The funds are allocated to the person with a disability, and are portable anywhere in Australia.

The management of funds should allow people with a disability the options to:

- receive the funds directly
- have control over the direction of service, with assistance accountability, co-ordination and financial management
- delegate all or some of the management and direction to a third party.

Blue Skies has experienced that the more the person has control over the direction and management of the service, the more likely:

- an appropriate service is provided
- increased empowerment is achieved
- the funds are used efficiently
- the service complements and helps build informal support networks.

People with a disability, however, are not immune to requesting and accepting poor service. Good outcomes are more likely if the person with a disability has a strong positive vision for their life, can plan effectively and direct the service to build on this plan. Many people with a disability have

learnt, through intentional strategies, to “envision, plan and build a good life” as a way of thinking³.

Blue Skies has observed that the sooner a person with a disability develops these skills, the more competent they become in taking control and the less likely they will succumb to “learned helplessness” by relying on services to make critical life decisions for them.

It follows that a disability care and support scheme should include intentional strategies to assist people with a disability to build capacity to envision, plan and direct their service. It also follows that if people with a disability and their families do not have the capacity at any particular time, they can obtain some interim assistance.

The scheme should include the cost of management within the total cost of support, so that people can transparently negotiate the level of this assistance with their service provider.

How should the amount of financial support and service entitlements of people be decided (and by whom)?

First and foremost:

- the person with a disability should decide what services they require to have their basic social, physical and emotional and spiritual needs met
- the person's needs change throughout their life so there is a need for regular review
- the system of allocating funds needs to be straightforward, with entitlements based on a transparent process with the predetermined unit costs
- the process should be timely, flexible and responsive to local community challenges and opportunities.

Blue Skies recommends that:

The decisions about the financial support and service entitlements should be made by an independent and community- based panel that is mindful of local challenges and opportunities.

The assessment process should use a strengths-based framework towards inclusion and participation rather than a deficit framework focusing on diagnosis and limitations.

A panel would request a strengths-based plan identifying:

³ Ward, J “*Planning for Now, Tomorrow and the Future*” -, Pave the Way, Mamre Association, December 2007, p10

- the vision and plan for inclusion and participation in the community of choice
- the support required:
 - first ascertaining the existing natural supports, opportunities and generic services that exist in the person's community and networks
 - then naming the paid support required to help build and maintain those natural supports, opportunities and generic services
- a management strategy that ensures:
 - an appropriate service is provided
 - empowerment is achieved
 - the funds are used efficiently
- A review period to ensure there is time and capacity to respond to changes in life developments, the disability itself, the person's capacities and skills, the environment and technological developments⁴.

Integral with the plan for support would be a plan for the aids and equipment required. Using the International Classification of Function, Disability and Health (ICF) and input from the person with a disability to consider personal preferences, the priorities can be defined as:

- the best combination of equipment, personal care and environmental design to meet their needs in all aspects of life and life changes
- good quality and long lasting equipment
- a holistic approach, that is, each piece of equipment works well and does not interfere with other equipment or supports
- support through the process of getting equipment, including equipment trial, training and maintenance⁵.

⁴ Cook & Hussey, 2008; de Jonge, Scherer, & Rodger, (2007)

⁵ de Jonge, Layton, Vicary – work-in-progress 2010

What services are needed and how should they be delivered?

What kinds of services particularly need to be increased or created?

Development of a specialised community based service system	Development of a network of specialised services which can respond to the individual needs of people with a disability in community and are structured to manage portability of funds.
Capacity building of people with a disability.	Focused effort is required to assist people with a disability to envision and plan positively. People with a disability need intentional assistance to preserve their inherent hopes and dreams and to confront any negative stereotypes and expectations of society they may encounter.
Community Capacity Building	Assisting communities to include people with a disability and to welcome them to participate. Then identifying, building and nurturing of supportive community relationships alongside and with people with a disability.
Research and development	Capacity to evaluate the outcomes of the scheme and to signpost changes required to identify avoidable wastage and to respond to society's expectations.
Safeguarding strategies	Safeguarding strategies, including independent advocacy, administrative appeals mechanism and simple, transparent accountability measures for both services and users.

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

Generally, the most responsive and cost effective services have the following features:

Appropriateness	The service is done by the right people at the right time in the right way and does not necessarily need to be repeated, improved, or any damage redressed.
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Matching the need	The people providing the service have attitudes, values, and cultural sensitivities which align with the person with a disability. The people have the skills and abilities to carry out the work.
Direction and management	The decision-making and co-ordination is done by the person with a disability or as close to the person with a disability as possible – preferably by the person—in a way that paid supports help build and complement informal networks of support.
Flexibility	The service can respond to changing need.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

Early empowerment	The sooner people with a disability and their families are envisioning, planning and building as a way of thinking, the more likely they will take charge of their life and the less likely they will succumb to a "learned helplessness".
Assistance when it is needed	The right amount of assistance at the right time by the right people, particularly for people with episodic conditions or crises situations, may have a short-term cost but is likely to avoid unnecessary long-term harm.
Early intervention and prevention	People will have less handicapping effects of their disability if they have optimal chance to learn and develop. People with acquired disability can be assisted to maintain their work, connections and interests so they can continue to live their life as before.
Inclusion at all costs	Unconditionally, paid service should be building on and complementing any informal supports and community connections that naturally exist. There is no excuse for the damaging of established relationships and networks and there is no place for the seclusion, congregation or sequestering of people with a disability for the convenience of the service provider.

How could a new scheme encourage the full participation by people with a disability and their carers in the community and work?

The scheme would benefit from the following three pronged approach:

Capacity building of people with a disability and families	The scheme will work best when there is investment in the envisioning, planning and decision making of people with disabilities and families.
Community builders	The scheme will work best when communities are able to invite, include and welcome the contributions of people with a disability. Most communities benefit from intentional assistance to do this. Community builders would catalyse and prepare opportunities for work, leisure and creativity for people with a disability.
Community navigators	The scheme will see optimal use of the funds if people with a disability are assisted to find work, leisure and creative opportunities in the community available to everyone.

How can a new system ensure that any good aspects of current approaches are preserved?

The scheme would benefit from gradual implementation, so that those people with a disability who are not ready or supported adequately to direct and manage their service would:

- continue to be supported by the established service structure
- be provided transitional assistance to become more self-determining.

The Blue Skies Team has experienced that once people with a disability and families experience the positive benefits of managing and directing their own service they are unlikely to return to the more paternalistic service structure.

What should be done in rural and remote areas where it is harder to get services?

Blue Skies acknowledges that access to specialist knowledge and advice will continue to be a challenge in rural and remote areas. However, the principle of supporting “in place” should prevail. The more people with a disability have the authority to manage and direct their own service, the

more likely local practical solutions will be found. (Local community boards will assist the person with a disability to envision and facilitate solutions).

People living in rural and remote areas often have networks of support in local communities. Flexibility and the ability to self-direct funding will mean that people can purchase support from these networks. Where specialist support is not available, people might need extra resources to travel to specialists or equipment manufacturing appointments. This needs to be factored into the scheme.

Ultimately, people's needs have to be met regardless of where they live. The system should reflect this in terms of finding a local solution first. When this is not possible, optimal use of technology and funding for people to travel to where they can access the supports and services should be provided. .

Funding

How should a new scheme be financed?

A no-fault National Disability Insurance scheme, paid as a levy by taxpayers, would ensure funds are available for those who currently have a disability, and those who may acquire one in future, due to illness, age, accident etc. That way, equity is possible amongst Australians regardless of disability.

A strategy will be required to convert existing government funds for disability support over time into this scheme.

How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

Ultimately it will be political will that ensures there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future. However there are key elements to the scheme which will inhibit a “blow-out of costs. They are:

Focus on
strengths and
abilities rather
than deficits

The recommended strengths-based planning will harness established informal supports, self reliance and community capacities, and encourage formal paid supports to complement and help build on support that is already there. People with a disability and their families may require assistance to envision a “good life” to plan for the future and to direct their service.

A deficit framework results in ever-expanding need. It typically disempowers people, ignores opportunities for inclusion and participation within established networks and communities, finds solutions mainly in specialist paid responses, and results in a culture of “learned helplessness”.

Direction and
management of
service by the
person with a
disability

When the person with a disability or their family plans, directs and manages the support, it is more likely to be the right amount of service by the right people at the right time.

This reduces unnecessary management and co-ordination costs.

The scheme
does not
compensate for
poor generic
services

Generic services, such as medical care, hospitals, housing, education and transport should meet the needs of people with a disability in the same way that these services meet the needs of other Australians.

Flexibility in who
is employed and
how they are
paid

For people with a disability to have the right amount of support by the right people at the right time, they will need access to a wide variety of people who could work within a wide variety of employment and contractual arrangements.

Timeliness

Early intervention, with the right equipment provided, will limit avoidable impairment, barriers, exclusion and loss of established natural networks.

Organising and implementing a new disability policy

What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?

Blue Skies recommends the following guidelines:

1. The system should allow for the person with a disability or their family to receive the funds, and direct and manage the service as first preference. The more the person with a disability or their family can manage the funds, more of the allocated funds can be used for direct service.
2. Optimising electronic processes will allow for transparent and simplified payment and accountability processes.
3. To ensure flexibility and a range of employment and contractual arrangements, all taxation options should be available; that is, Statement by Supplier (for flexible time-limited service, ABNs (for contractors with particular skills), Pay As You Go (for substantial and ongoing employment).
4. While complaints processes within services are important for a service to improve, the most powerful strategy for improvement is the buying power of the consumer. If the person with a disability is not satisfied with the service, they can buy the service elsewhere.
5. Any auditing process of services assigns priority to outcomes for people with a disability rather than quality of systems.
6. The investment in information and training made in people with a disability and families is comparable with that offered to service providers.
7. Employment requirements of support staff allows for "ordinary local folk" to be engaged. People with a disability will typically choose and keep staff with compatible values and cultural backgrounds over their training and experience.

How long would be needed to start a new scheme, and what should happen in the interim?

Blue Skies recommends:

- a clear bipartisan commitment and timeline should be made to people with a disability and their families in Australia to adopt a National Disability Insurance Scheme

- the development of a national system of local assessment boards, a register of accredited disability service providers and a card system (similar to Medicare) for payment
- a series of pilot schemes to be implemented to establish local boards, from which a national system would be based
- an intentional strategy be developed through community navigators and disability advocates, to assist people with a disability and their families to envision and plan for a “good life” and to build and maintain their natural networks.