



**A Scope Submission for the**

**National Disability Strategy Consultation**

**November 2008**

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## 1. Overview

Scope welcomes the Commonwealth Government's commitment to developing and implementing a National Disability Strategy. It is long overdue. The sorry statistics outlined in the Government's Discussion Paper are an important reminder of how far Australia is lagging behind in ensuring people with disabilities have access to the rights and entitlements enjoyed by their fellow Australians.

As it is currently framed the proposed aim of the National Disability Strategy is highly ambitious. If properly established and implemented, the Strategy will be transformational. People with disabilities can expect a better life as a result of such work. However, it is critical to get the foundations right.

Scope works alongside Australians who are most likely to be overlooked when disability policy is framed. We support of over 6000 Australians with disabilities, with a particular focus on people with significant physical and multiple disabilities.

We have information that is critical to the success of the Strategy. By working with people with the highest support needs we have been able to demonstrate that this overlooked group can be, in fact must be, given the full opportunities to participate in the life of the community. To do anything less is to perpetuate and even entrench the disadvantage experienced by people with the highest support needs.

This means the Government must ensure the Strategy fully includes the needs and aspirations of Australians with the highest support needs.

**To ensure people with the highest support needs receive equal benefit from a National Disability Strategy it must:**

- **Ensure the voice of people with higher support needs is heard at every stage**
- **Be based on principles of universal design and inclusion for all**
- **Enshrine the concept that we plan for the highest needs first**
- **Move beyond running community awareness campaigns to funding community building and community development strategies focusing on the inclusion of people with disabilities**
- **Ensure research and innovation take place to both monitor and drive change**
- **Measure success by moving beyond "objective" population-based evidence. While such measures are important, we must also look for outcome measures that are based on what people with disabilities identify as important – it is their life.**

These themes are explored in more detail in the submission. Further, Scope outlines seven possible Flagship Initiatives that would symbolize the ambitions of a National Disability Strategy. These initiatives include:

- *Create-ability* – A National Arts and Disability Strategy
- *Included* – A Strategy to Create Welcoming and Inclusive Communities
- *Pathways to Employment* – A Strategy to Provide Employment for People with Higher Support Needs
- *National Communication Initiative* – An Initiative to Promote Outcomes for People with Complex Communication Needs
- *Disability Innovation Fund* – A 3-year Strategy to Kick Start the Investment in Innovation
- *National Disability Research Agenda*
- *Office for Disability Outcomes*

## 2. About Scope

Scope is a not-for-profit organisation providing innovative disability services throughout Victoria to more than 6,000 children and adults with physical and multiple disabilities. Thousands more people intermittently access our information, support and assessment services on a casual basis. Scope supports people with disabilities to achieve their potential in welcoming and inclusive communities.

Central to Scope's work is to ensure the members of our community "See the person, not the disability". Therefore, Scope focuses on overcoming the personal, structural and attitudinal barriers that prevent people with disability from participating in community life and works to make our community more inclusive, more accessible and more welcoming.

Scope has long-standing expertise in supporting people with significant support needs. This is a result of a commitment to work with people who many other organisations have considered "too hard" to work with. Many clients with disabilities have very high levels of physical and intellectual disability, often with complex health needs.

## 3. About People with Higher Support Needs

Scope supports many people with a range of disabilities. However, we have a strong historical connection to people with significant physical and multiple disabilities. Here are some examples of who we work with and the life they live:





## Just Working Out

An assessment by a physiotherapist, installation of a hoist, a call to check the lift is working and to book the stretching room, then another call to book the bus, driver and staff and then Ashley can “pop down to the gym”.



## Catching the Train

To catch the train, staff checked the accessibility of all the stations and platforms she needs, Lennette had years of travel, safety and etiquette training, she learnt to count and handle money, when and how to buy her ticket. Lennette needs to be in the right place on the platform so the driver can see her and then she can catch the train!

## **4. What are the Aspirations of People with Significant Physical and Multiple Disabilities?**

Scope is concerned at the limited opportunity for people with higher support needs to participate in the consultation process for the National Disability Strategy. To try and address this problem, we have invested in supporting people who use our services to contribute directly to the national consultation process, so that their voices can be heard without being filtered by others.

However, Scope has other information from this critical group that is relevant to the development of a National Disability Strategy that is inclusive of all people with disabilities. Because of our ongoing desire to ensure our services are aligned to the needs of service users, we regularly consult with people with higher support needs, particularly people with significant physical and multiple disabilities. The results of these consultations are important in the context of the Strategy, because they provide information about this group which may otherwise be “missing” from the Strategy consultations.

The following key themes summarise some of the issues and aspirations of people with higher support needs, including people “living with profound disability and complex needs”. These issues and aspirations were identified by independent consultants LIME Management Group to support Scope’s strategic planning.

### General

- People with significant physical and multiple disabilities like, and participate in, a wide range of pursuits and enjoyments in their everyday lives in the same way as people without a disability. Similarly, their hopes and dreams for the future are striking in terms of their ‘mainstream’ nature.
- People are experiencing a service trend where their formal activities and informal opportunities are becoming better aligned with what they want to do and the type of lifestyle they want to have. The people who were consulted want more of this.
- The hopes and aspirations of people reflect their different life stages and ages. Those hopes and aspirations focus on the following areas: education and employment; community access; retirement; holidays and recreation; transport; personal needs and housing.
- For younger people there is the expressed hope of leaving home, studying, going to university, having a career or a job and mixing with their own age group including young people without a disability. For older people there is the desire to reduce their working hours, have more free time at home and more community access.

### Community Access and Relationships

- Community access and relationships are seen to be of great importance. There appeared to be a lot of informal and formal community access occurring and people wanted more. People gain satisfaction and enjoyment from education, employment, relationships, and just being part of the community. Our impression is that younger clients are more engaged in community access while older clients are mostly attending day centres during the week.
- In addition people enjoy evenings out, weekends away and weekend outings and holidays and the majority of people want more of this ‘out in the world’ lifestyle and feeling.

### Levels of Support

- The service system appears to offer little assistance to people if their disability need is low. This can mean that the person with low disability needs may receive so little assistance that their life is a major struggle which could be alleviated with a little more support.
- Similarly, people with high support needs may not receive sufficient support in some areas as their physical requirements take up a lot of their time. For example in residential services, the funding model limits community access for people with high needs and places a high work load on staff who attempt community access for people with high needs.

- Some people appear to be falling through the gaps of the total service system. This raises the issue of needing the ‘right’ service system response for the client to be successfully assisted.

#### Autonomy, Dignity and Respect

- People want more control over their lives, respect, openness, to be given a ‘voice’ and to be listened to.

#### Transport

- Transport difficulties were raised regularly by people particularly in the areas of public transport and taxis.

#### Retirement

- Semi-retirement or retirement options to cater for middle aged and older people do not appear to be happening. People expressed interest in semi-retirement but there did not appear to be changed activities, timetables, and flexibility to stay at home for full or part days or have more informal community access, particularly for people working in supported employment services.

#### Summary

These themes highlight that people with high support needs aspire to the same things as their fellow Australians. It is clear from that their needs and aspirations cover all elements of life and citizenship, which means that a whole-of-government response is required.

Scope notes that the Discussion Paper proposes an aim for the National Disability Strategy. That aim is:

*to increase the social, economic and cultural participation of people with disability, to eliminate the discrimination experienced by them and to improve disability support services for them, their families and carers. For those living with profound disability and complex needs, we must ensure support and living arrangements meet the same standards of dignity and choice as all Australians expect.*

It is important to clarify that the statement about people “living with profound disability and complex needs” means that appropriate support and living arrangements for these people is seen as additional to the broad aims of participation and the elimination of discrimination.

**Scope strongly advocates for the Government to ensure it does not create a two-tier strategy, with people “living with profound disability and complex needs” in the second tier.**

## **5. The Convention on the Rights of Persons with Disabilities**

Scope is aware that a number of individuals and organisations representing people with disabilities are proposing that the Convention on the Rights of Persons with Disabilities provide the framework for a National Disability Strategy. Scope endorses this position.

## 6. Measuring Outcomes – A proposed framework for measuring success for the National Disability Strategy

Scope wishes to highlight the lack of relevant outcome measures in the disability area. While there has been a lot of talk about measuring outcomes and even attempts at identifying outcomes that should be measured, this area is underdeveloped. A careful analysis of work done internationally highlights that even where outcomes have been identified there has been little or no work done on method development – there are few valid and reliable research tools to measure outcomes.

In partnership with Deakin University, Scope has been working for the past 4 years on developing an Outcomes Framework that enables people to measure the success of strategies designed to enable people with disabilities to have a better life. The Framework is constructed around concepts of citizenship. Just as importantly, it identifies that there are outcomes not just for people with disabilities and their families, but also outcomes for services and outcomes for communities. All these dimensions are incorporated into what is considered to be ‘success’.

A number of research tools (methods) have been developed that enable people to research and evaluate progress in relation to a number of outcome domains.

Of particular importance is the Framework’s emphasis on the experience of people with disabilities themselves. Unlike population-based ‘objective’ measures, this Framework is designed to place the experiences and priorities of people with disabilities at the heart of the enquiry. Population-based measures are important, but they are only part of the picture.

Scope argues that the Outcomes Framework outlined here, together with the associated measurement tools currently being developed, would be of great value in formulating and measuring outcomes for the National Disability Strategy.

The Framework is outlined in Table 1 below.

**Table 1: Outcomes Framework for Disability (Wilson, 2008)**

Outcome Domain	Definition	Key ideas /sub domains
<b>Personal wellbeing and civil citizenship</b>	The experiences and opportunities of personal life including a person’s agency (to make meaning, act, influence and contribute) in the areas of health, wellbeing, happiness, autonomy, identity, future, values, thought, and expression.	Personhood, identity construction – sense of self Happiness Self esteem Wellbeing Health and safety Freedom of thought, expression, speech Individuality Autonomy Choice Self determination Individual freedoms: Liberty, Conclude valid contracts, Justice, Values
<b>Social Citizenship</b>	The experiences and opportunities of life in the social domain including a person’s agency (to make meaning, act, influence and contribute) in the areas of relationship, community connectedness and belonging.	Networks: <ul style="list-style-type: none"> <li>• bonding (horizontal / closed)</li> <li>• bridging (between groups)</li> <li>• linking (to authority)</li> </ul> Relationships Friendships (intimate → acquaintances)

		Community connectedness / belonging Community inclusion Loneliness, isolation
<b>Political Citizenship</b>	The experiences and opportunities of life in the political domain including a person's agency (to make meaning, act, influence and contribute) in the areas of public decision making, civic activity, consultation, advocacy and lobbying.	Civic activity Civic duties: rights and responsibilities Advocacy Lobbying Democracy Choice Leadership Political participation
<b>Cultural citizenship</b>	The experiences and opportunities of life in the cultural domain including a person's agency (to make meaning, act, influence and contribute) in the areas of cultural production and participation, broader attitude change and development, and recreational activities.	Participation in cultural or recreational events and activities. Influencing attitude / behaviour change Cultural production: <ul style="list-style-type: none"> <li>• Performance</li> <li>• Art</li> <li>• Writing / authorship</li> </ul>
<b>Economic citizenship</b>	The experiences and opportunities of life in the economic domain including a person's agency (to make meaning, act, influence and contribute) in the areas of employment, enterprise and a range of economic roles (e.g. as consumers and income generators).	Access to economic domain Employment Consumer roles Home/ property ownership Income level and source Direct payments Retirement Industrial relations agency
<b>Educational citizenship</b>	The experiences and opportunities of life in the economic domain including a person's agency (to make meaning, act, influence and contribute) in the areas of education, training, professional development, knowledge and skills development.	Education and training (at all ages) Professional development Skills development Knowledge development
<b>Spiritual citizenship</b>	The experiences and opportunities of life in the religious and spiritual domain including a person's agency (to make meaning, act, influence and contribute) in the areas of their beliefs and the practices associated with these.	Beliefs Religion Spirituality
<b>Environmental citizenship</b>	The experiences and opportunities of life in the environmental domain including a person's agency (to make meaning, act, influence and contribute) in relation to their environment including constructed environments, public and private space.	Access to physical environment Shaping of/access to public space Shaping of/access to private space (housing etc) Shaping of/access to public transport Built environment / constructed space Universal design

## **7. Seven Flagship Initiatives**

Scope argues that there is a need for flagship initiatives to drive key changes and to provide bold symbols of the National Disability Strategy. These initiatives would focus on areas where critical work must be undertaken if the National Disability Strategy is to achieve its aims. These initiatives could be embedded in appropriate Government Departments to emphasise the whole-of-Government focus of the Strategy, but monitored through an Office for Disability Outcomes within the Department of the Prime Minister and Cabinet.

### **7.1 *Create-ability* – A National Arts and Disability Strategy**

To be overseen by the Department of the Environment, Water, Heritage and the Arts. Commonwealth funding would be matched by State funding, with Commonwealth coordination underpinned by State-specific strategies.

*Create-ability* would implement the key recommendations of the recent national review of Disability and Arts. The focus would be to support people with disabilities as creative artists. Its goal would be to establish Australia as the international leader in terms of arts and disability. Opportunities would be funded for artists in both traditional and emerging media: theatre, dance, fine arts, digital media etc. The Strategy would include a priority on establishing international linkages by artists with disabilities.

### **7.2 *Included* – A Strategy to Create Welcoming and Inclusive Communities**

To be overseen by the Department of Families, Housing, Community Services and Indigenous Affairs.

*Included* would be a partnership of Governments, people with disabilities, families and support services that would go beyond simplistic concepts of disability awareness campaigns and physical access requirements to implement strategies that create communities that are genuinely inclusive and welcoming of people with disabilities. This would be done through a broad-based strategy that identifies and implements innovations in inclusive practice. Inclusion would be considered against the broad criteria of economic, social and cultural inclusion and draw on internationally proven community building and community development strategies.

*Included* would encourage a holistic approach to inclusion for people with disabilities. It would, for example, fund best practice programs to creating inclusive shopping centres, health services, community centre and other “places and spaces” in the community. Its framework would incorporate: understanding the experience of people with disabilities in these contexts, considering physical elements such as access, design and location, and considering social/cultural elements such as policy, the skills, attitudes and behaviours of staff, and interactions with fellow citizens.

The Strategy would include a National Disability Inclusion Award for communities that have achieved excellence in the economic, social and cultural inclusion of people with disabilities.

### **7.3 *Pathways to Employment* – A Strategy to Provide Employment for People with High Support Needs**

To be overseen by the Department of Employment, Education and Workplace Relations

*Pathways to Employment* would actively seek out innovative approaches to employing people with high support needs. With an initial focus on an international search best practice employment initiatives for marginalised people in both developed and developing countries, this strategy

would then pilot a number of initiatives before embedding successful initiatives into funding policy to be implemented through Disability Employment Network services.

Of equal importance would be the development of active strategies to enable people with disabilities to take up opportunities currently flowing through the broader reform of VET and other pathways to employment. This would address the dearth of such places in the vocational education system being taken up by people with disabilities, particularly people with high support needs.

#### **7.4 *National Communication Initiative* – An Initiative to Promote Outcomes for People with Complex Communication Needs**

To be overseen by the Department of Families, Housing, Community Services and Indigenous Affairs.

The *National Communication Initiative* would draw on the world-first Victorian Communication Initiative, which has focused on establishing a statewide service providing information and resources for people with little or no speech (complex communication needs). Services and supports would be provided through a community capacity building framework in order to build community awareness and to support community participation.

#### **7.5 *Disability Innovation Fund* – A 3-year Strategy to Kick Start the Investment in Innovation**

To be overseen by the Department of Innovation, Industry, Science and Research.

The not-for-profit sector is noted for its ability to innovate, as can be seen by the myriad social enterprises that currently exist. However, innovation in the area of disability has been chronically underfunded. Establishing a fund to support and encourage the uptake of innovative practice by people with disabilities, disability service providers and community service providers would ensure innovations would tap significant, but currently unrealized, potential.

Working in partnership with philanthropists and business, the Government could create a pool of funding that would provide a “kick-start” to innovation.

#### **7.6 *National Disability Research Agenda***

To be overseen by the Department of Innovation, Industry, Science and Research.

The *National Disability Research Agenda* would have the following overarching research goal:

##### **A better life for people with disabilities**

The emphasis of the agenda would be the day-to-day realities of living with disability. It would have a whole-of life focus. It would acknowledge that people with disabilities have friends and families and that they are members of communities.

It would be about real outcomes for real people.

It would focus primarily on research that supports people with disabilities to have a better life today. It would assume that people with disabilities have something to say, that they have the

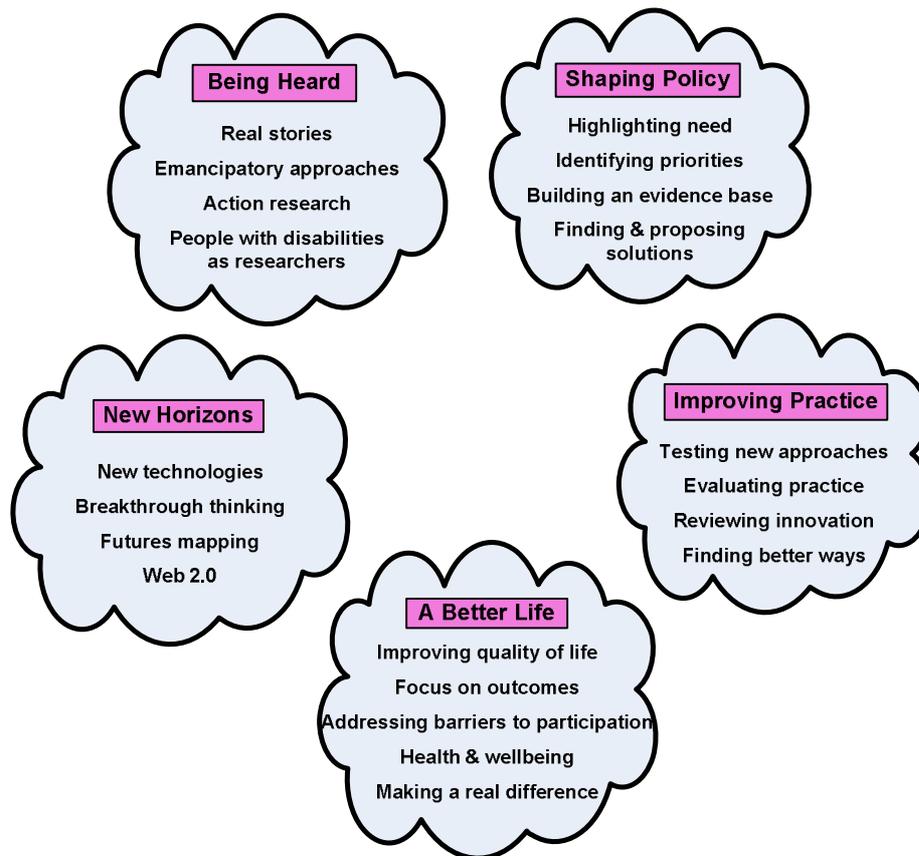
capacity to be more than ‘objects’ to be observed, that they have a rich inner life that can be communicated.

The Agenda would focus on the following goals:

- ① **Achieving greater social inclusion for people with disabilities**
- ② **Services that deliver real outcomes for each person**
- ③ **Finding new ways to support people with disabilities to have a better life**

It would have the following Outcome Areas:

### RESEARCH AGENDA OUTCOME AREAS



Scope notes that less than 1% of the funding accounted for through the CSTDA (and now the National Disability Agreement) is allocated to Research. This makes disability research the most underfunded area of research in any major sector in Australia, and it also makes Australia the poorest performing the developed world in this area. Developing and funding a *National Disability Research Agenda* would rectify this.

#### 7.7 *Office for Disability Outcomes*

The initiatives outlined above are proposed as part of a whole-of-government strategy. To ensure these, together with the broader aims of the National Disability Strategy, are achieved, an Office for Disability Outcomes is proposed. This Office would be part of the Department of Prime Minister and Cabinet. It would have responsibility for coordinating the broader initiative, ensuring

it links within the broader inclusion strategies of the government, and ensuring accountability for the diverse initiatives and works arising from the National Disability Strategy.

## **8. Bringing It All Together - A Systems Response**

Scope notes the plethora of disability-related reforms, committees, groups and strategies currently underway at a national level. While this highlights the serious commitment of the Government to address the long-neglected area of disability, it raises the importance of a coordinated approach to reform.

At the moment, it is hard to get a sense of a single organizing principle or mechanism to the range of reforms. Yet this is critical. While disability does touch on almost all areas of government responsibility an approach that is not coordinated will be much less efficient and effective than it could be.

A systems approach will be vital to achieve the benefits that deep reform can bring. To this end, the National Disability Strategy needs to engage with the current work on many fronts and bring it all together. While there is complexity this can only be effectively managed through working through how the whole comes together in the one system.

**Scope strongly recommends that the National Disability Strategy embrace a systems approach and that it be used to pull together the many activities currently taking place on the national policy front.**

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## **APPENDIX A**

### **The Five Outcome Areas for a National Disability Research Agenda**

Scope proposes five outcome areas as the foundations of a National Disability Research Agenda. These are:

- Being Heard
- Shaping Policy
- Improving Practice
- A Better Life
- New Horizons

This section provides further detail regarding each of these outcome areas.

#### **Being Heard**

Research designed to ensure people with disabilities and families are heard, giving voice to their needs and aspirations, to their thoughts on the issues they face, and to the solutions that they consider to be important. This is research that sees people as more than passive subjects of the research. Here they become active partners in the research process.

#### **Shaping Policy**

Research designed to build an evidence base to highlight needs, identify priorities and to find and propose solutions. This is research that will be used to influence policy and shape community awareness in relation to issues that are important to people with disabilities and their families.

#### **Improving Practice**

Research designed to test new approaches, evaluate practice, uncover innovation and find better ways of working. This includes testing and evaluating new service approaches and product development. The focus is on the way disability and community organisations do their work. Of particular importance for the current time is a focus on person centred approaches and strategies to create more inclusive communities.

#### **A Better Life**

Research that aims to improve the quality of life of people with disabilities and their families. This research may not relate to disability or community services at all. Rather, the focus is on achieving improved outcomes for people, on addressing barriers to participation, on researching those things that will make the biggest difference.

#### **New Horizons**

Research designed to bring breakthrough approaches into the lives of people with disabilities. Opportunities are emerging every day in such areas as Web 2.0, robotics, prosthetics and even the financial and economic worlds. It involves proposing and testing possibilities, funding and undertaking research to accelerate the transfer of great ideas into everyday realities for people with disabilities.