# *Disability expectations*

## Investing in a better life, a stronger Australia

*Achieving better outcomes for people with a disability and their families*

*November 2011*

pwc

# Foreword

*The National Disability Insurance Scheme (NDIS) was put forward by the Productivity Commission in its report Disability Care and Support, which was submitted to government on 31 July 2011 and publicly released by the Prime Minister on 10 August 2011. The NDIS proposes a way forward for Australia.*

*PwC brought together an expert team with extensive experience in the disability support system. The aim of the group has been to answer the question "What is required to deliver the NDIS?"*

*This paper provides a brief history of disability in Australia and, as part of its focus, draws on international experience and comparisons. One of the most telling and challenging statistics is that Australia ranks 21st out of 29 OECD countries in employment participation rates for those with a disability. In addition, around 45% of those with a disability in Australia are living either near or below the poverty line. These facts alone show us that we need to change.*

*The paper explores the NDIS from different perspectives starting with the person with a disability, then the family, then support organisations, and finally the government or National Disability Insurance Agency (NDIA).*

*The biggest challenge for Australia is to provide an environment for change which allows for a cultural shift across all parts of our society. Active participation of those with a disability in society generally can only occur with a change in attitude. This is something that can't be legislated; people need to see the reason why change is important.*

*I urge you to think about the four principles we have put forward in this paper: Fairness, Facilitation, Choice and Inclusion and ask whether there is anything you or your organisation can do to help bring about change.*

*Improving the lives of those with a disability is the responsibility of all Australians.*

***Chris Bennett***
Partner
Government Sector Leader
PwC

Her Excellency Ms Quentin Bryce AC
Governor-General of the Commonwealth of Australia

## Message from Her Excellency Ms Quentin Bryce, AC CVO
## Governor-General of the Commonwealth of Australia

*for "Disability Expectations: Investing in a better life, a stronger Australia*

As a nation, we take pride in the principles of fairness and equity.

Our history has many examples of Australians struggling for equality of opportunity and equal rights for the disadvantaged among us, however, people living with a disability are, too often, left behind, even though their skills and experience are of great value.

Gradual progress has been made towards reform of disability services. This paper *"Disability Expectations: Investing in a better life, a stronger Australia"*, is an important step in that process.

The paper has been developed by PwC and their Thought Leadership Advisory Group. It reflects on past and current disadvantages faced by Australians living with disability, and it discusses how to support them in a new era of change and opportunity.

The paper highlights the need for a cultural shift in attitudes towards Australians living with disability; from passive sympathy and understanding, to actively encouraging and championing a better quality of life.

I commend the discussion and collaboration which has produced this paper, and I support its aim to inspire all of us to make a difference to the lives of our fellow Australians living with disability.

Quentin Bryce.

18 · 11 · 2011

GOVERNMENT HOUSE CANBERRA ACT 2600 AUSTRALIA
TELEPHONE +61(2) 6283 3525 FACSIMILE +61(2) 6283 3595

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# *Disability expectations: Investing in a better life, a stronger Australia – Overview*

*The imperative for changing the disability experience in Australia is clear. Change must occur at the broadest level for improvement to be seen at the level of the individual. The National Disability Insurance Scheme (NDIS), in parallel with strong policy, whole-of-government accountability, and culture change are the keys to realise reform. The necessity to act now and introduce an NDIS is undeniable – it is required for the economic safety and security of Australia, it provides a fair go for all Australians. It is the right thing to do for the future wealth of Australia – in both economic and social terms.*

Australia is the lucky country, where most Australians have the opportunity to dream without limit. Yet our largest minority – people with a disability – are not afforded the basic rights others take for granted, let alone the relative luxury of leading a good life. That is, approximately four million people living with a disability in Australia are at risk of or are currently being treated unfairly. This is explicitly highlighted in the Productivity Commission's (PC) report.

This should resonate with every Australian, because anyone could find themselves living with a disability at some point in their lives.

## Investment in change: Policy, system and culture

### *A fair go for all Australians*

Broader access to the economy and society has been at best haphazard or at worst a near complete 'shut-out'[1] for many Australians living with a disability. If we are committed to being a fair and decent Australia, we must invest in real change, which gives power and dignity to the individual.

Change is necessary because Australia's overall performance in outcome and cultural terms for people with a disability, their families and carers has been poor. Policy promises of fairness and basic human rights have gone unfulfilled. Active pursuit of system and societal change in combination with the NDIS is the most obvious and achievable way of:

- providing an entitlement rather than welfare-based access for 410,000 Australians
- changing the cultural and material environment
- explicitly changing the way mainstream and specialist disability services interact with people living with a disability.

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[1] Australian Government. (2009). Shut Out: The experience of people with disability and their families in Australia. National Disability Strategy Consultation Report. Prepared by the National People with Disabilities and Carer Council.

## *The economic safety and security of Australia*

The population of Australia is ageing – so, while there are currently five people of working age for every person aged 65 and over, this number will almost halve (2.7) by 2050.[2] In the face of this dilemma, people of working age with a disability still face barriers to transport, employment, education and support, limiting their opportunity to contribute as productive members of society.

In 2009, approximately 1.3 million[3] Australians had a severe/profound core activity limitation. These 1.3 million people (and other people with a disability) were supported by approximately 772,000[4] (calculated on an FTE basis) informal carers.

In 2099, it is estimated that approximately 4 million[5] people will have a severe/profound core activity limitation in Australia – more than triple the current number. However, the Australian population is estimated only to double[6] over this same time period; hence, it is likely that the same amount of informal care will not be available in the future to support people with disabilities. The formal workforce will need to grow significantly to meet this increasing demand.

In the international context, Australia has significant opportunity to improve in terms of disability-related expenditure, employment performance and relative poverty:

- An international comparison of disability-related expenditure (to the extent that this is possible) indicates that, compared with other countries, Australia has a lower level of spending as a share of GDP on long-term care for people under the age of 65. Expenditure is more than double in the Scandinavian countries of Denmark, Sweden and Norway, and slightly less than double in the United Kingdom when compared with Australia.[7] This is still the case when disability income payments are included
- The current employment rate of people with disabilities in Australia is low against the OECD average. People with a disability in Australia are only half (50%) as likely to be employed as people without a disability.[8] In comparison:
  - For the OECD, the relativity is 60%.
  - Considering the top eight OECD countries, the relativity is closer to 70%.[9]
- Forty-five per cent of people with a disability in Australia live in or near poverty, more than double the OECD average of 22%. Furthermore, Australia has a relative poverty risk (ie people with a disability compared to people without a disability) of 2.7, against the OECD average of 1.6.[10]

*Every week, five more Australians sustain a spinal cord injury and 10 to 15 sustain a severe traumatic brain injury.*

*Every two hours, an Australian child will be diagnosed with an intellectual disability.*

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[2] Commonwealth of Australia. (2010). Australia to 2050: Future challenges. Intergenerational Report 2010.

[3] ABS. (2009). Survey of Disability, Ageing and Carers (SDAC) CURF, ABS Population Projections, 2006 – 2101, Series B. Cat. no. 3222.0.

[4] ABS. (2009). SDAC CURF, PwC calculations.

[5] ABS. (2009). Survey of Disability, Ageing and Carers (SDAC) CURF, ABS Population Projections, 2006 – 2101, Series B. Cat. no. 3222.0.

[6] ABS. (2008). Population Projections, 2006 – 2101, Series B. Cat. no. 3222.0.

[7] Productivity Commission (PC). (2011). Disability Care and Support. Productivity Commission Inquiry Report. No. 54, 31 July 2011.

[8] Organisation for Economic Co-operation and Development (OECD). (2010). Sickness, Disability and Work: Breaking the Barriers – A Synthesis of Findings across OECD Countries.

[9] Ibid.

[10] OECD. (2009). Sickness, disability and work: Keeping on track in the economic downturn – Background paper.

## NDIS: An essential vehicle for change

The NDIS is a funding, support and governance mechanism that commits to providing people with a disability the opportunity to live fulfilling and active lives.

The scheme provides an opportunity for evolution in disability as we know it in Australia. It offers a platform for reform, and presents an opportunity for landmark change achieved in the teeth of straitened national and international circumstances. The NDIS will secure for the government that implements it a place in history. Just as it will for the government that does not.

The NDIS is not only the right thing to do, it is necessary for the future wealth of Australia's economy and society. It will make life better for people with a disability and their families while being cost effective.

The scheme is underpinned by an insurance model:

- It is based on an estimate of the reasonable and necessary support need of people with a disability
- It supports and funds the need in a responsible way
- It encourages active participation by people with a disability
- It manages risk and cost escalation.

The NDIS is the opposite of a welfare model and will make a positive contribution to Australia's productivity.

### The NDIS, within a package of reforms,[11] can achieve strong economic and fiscal gains

- Increased employment participation by people with a disability in the order of an additional 370,000 people in 2050[12]
- Additional GDP of almost $50 billion in 2050, which equates to a further 1.4% contribution to GDP[13]
- Increased employment participation by carers, in terms of about 80,000 carers entering the workforce or an increase in the number of hours worked[14]
- A fiscal gain of $1.5 billion in GDP per annum as a result of increased employment participation by carers.[15]

The NDIS is an economically responsible proposal, providing an investment in people with a disability and in the future of Australia. It pays for itself.

*One in five Australians has a disability.*

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[11] Note that these benefits are based on assumptions described in subsequent sections.
[12] OECD, 2010, op.cit., PwC calculations.
[13] Ibid.
[14] PC. (2011). Disability Care and Support. Productivity Commission Inquiry Report. No. 54, 31 July 2011.
[15] Ibid.

# *Introduction*

*A cultural change within our society is required to facilitate reform in the disability sector. This involves increasing awareness, educating widely and shifting attitudes to move towards genuine community inclusion. Disability expectations: Investing in a better life, a stronger Australia briefly traces the history of disability entitlement, services and policy, considers the PC's report, and asks what needs to change if the NDIS is to make a meaningful difference.*

## Purpose of this paper

In an Australian population of a little over 22 million people, about 4 million, or 20%, report as having a disability resulting from a health condition. Nearly 1.3 million people have a "profound or severe disability".

To put this into perspective:

- Every 7 hours, an Australian child is diagnosed with an autism spectrum disorder
- Every 15 hours, a child is born with cerebral palsy.

Almost one in two people with a disability in Australia live in or near poverty (45%). This is more than 2.5 times the rate of poverty experienced in the general population and more than double the OECD average of 22%.[16] The OECD average for relative poverty risk is approximately 1.6, which indicates that people with a disability tend to have a poverty risk about 1.6 times higher than people without a disability. Australia is by far the worst performer on this indicator, ranking 27th out of 27 OECD countries, with a relative poverty risk of 2.7.[17]

Despite enabling Commonwealth and state legislation dating back over 20 years, and a series of across-jurisdictional agreements to support people with a disability, the current disability support system is underperforming and requires an overhaul.

This paper explores the history and nature of disability and proposes a series of principles and recommendations which may help frame the implementation agenda for the Productivity Commission's proposals.

## Productivity Commission report

On 10 August 2011 Prime Minister Gillard released the PC's final report, Disability Care and Support, which sets out a vision for an entirely new model for providing care and support for people with a disability in Australia. The PC recommended a new national funding system and locally coordinated support system to provide people with a disability an opportunity to live fulfilling and active lives.

The report identifies the current disability support system as "underfunded, unfair, fragmented and inefficient" and advocates major reform to address:

- the current focus on the maintenance of service delivery systems rather than the satisfaction of the individual needs of those living with a disability
- unsustainable demand pressures, particularly as the current generation of family carers age
- multiple and complex state/territory systems including multiple assessment and delivery systems and inconsistent criteria for receiving support
- vertical fiscal imbalance – the principal government funders (state/territory) are not able to meet the future funding levels required, either to generate reform or even to meet current demand levels.

The four challenges outlined make the current system a barrier to entry into the everyday life of the community for many people living with a disability, and into specific areas of participation, such as the labour market. While the case for reform appears strong, it is clear that many practical challenges must be addressed if the separate state and territory systems are to be replaced with a single integrated funding and governance mechanism which is flexible and well-funded enough to meet individuals' needs, and achieve individual citizenhood, in a sustainable way.

"Citizenhood... an active lifestyle that has the prospect of fulfilment for the person concerned. Such a lifestyle is where, as part of a personally defined set of lifestyle choices, the person is in and part of their local community, contributing and growing through involvement in meaningful valued activities, and participating in a network of relationships characterised by acceptance, belonging and love."[18]

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[16] OECD. (2009). Sickness, disability and work: Keeping on track in the economic downturn – Background paper.

[17] Ibid.

[18] Williams, R. (2010). Model of citizenhood support – Discussion Paper. Julia Farr Association. p. 3

## *Guiding principles*

*We propose four key principles that should underpin the future development of disability support in Australia – **fairness** by way of equal rights; **facilitation** and **choice** in exercising rights; and **inclusion** through the removal of obstacles to access and participation. These principles touch on the critical intersections within and beyond the system and underpin the points of view presented in this paper.*

### 1. People with a disability have equal rights ➔ FAIRNESS

While the recognition of equal rights among peoples of all races, colours and creeds is now near universally established, those with a disability still struggle on the margins of recognition.

By being among the first countries to ratify the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), Australia has recognised that equal rights extend to people with a disability.

### 2. Supports are needed to allow people with a disability to exercise their rights ➔ FACILITATION

People with a disability have been denied access, hidden and ignored. They and their families are arguably the most disadvantaged of all Australians across much of our society.

If people with a disability are to exercise their human rights, they need a range of facilitators to help them negotiate this 'inaccessible' able-bodied world.

### 3. Individuals with a disability should have choice in prescribing their access needs ➔ CHOICE

A critical component of the NDIS framework is the dismantling of rationed, block-funded government purchasing of a narrowly defined suite of services.

Individuals with a disability will have the purchasing power to choose what their supports look like.

### 4. Cultural, systemic and environmental obstacles to access and participation for people with a disability should be removed ➔ INCLUSION

A potential limiting factor for successful change relates to the current obstacles to allowing people with a disability access to mainstream services.

Australian governments and community need to work together to systematically facilitate access to mainstream services for all people.

While at first glance these principles seem self-evident, the current system is a very long way from satisfying them, and the path to achievement will be long and difficult, requiring shifts in attitude and expectation.

The PC report provides a detailed schema of what the support system should look like, and what should be its component parts. In this paper we attempt to peel back some of the layers of the proposed system to understand the entrenched feelings and behaviours that need to change, and the transitional milestones that need to be achieved. We take a broad view in highlighting the need for fundamental cultural change and infrastructure development if the support system is to attain its maximum effectiveness.

The next logical step in making the necessary investment in progress towards an Australia that gives power and dignity to the individual – a fair go for all Australians – is to take action. At a minimum, we put forward four overarching actions that align with the assumptions of fairness, facilitation, choice and inclusion, while also reflecting the importance of achieving results through a focus on outcomes.

## *What needs to be done?*

*Bringing the guiding principles to life*

### 1. Bring alive the National Disability Strategy ➔ FAIRNESS

The National Disability Strategy needs to be formalised as a comprehensive national plan developed and agreed by all levels of government, and with agreed and widely published measurable targets and milestones.

As part of this, a frank acknowledgment of the current situation and the recent past will allow Australians living with a disability and the general public to resolve issues and move forward.

### 2. Commit to a funding, support and governance mechanism that empowers individuals ➔ FACILITATION & CHOICE

A very real and transparent catalyst in launching the rights plan is to fund it adequately and responsibly, based on outcomes and choice. To do this, we recommend the following:

A. Expand and clarify commitment to the NDIS – The funding stream provided by the NDIS is overdue – and it is an absolute necessity if Australia is to fulfil its obligations to Australians with a disability. The Commonwealth and the Council of Australian Governments (COAG) have supported the vision of the PC report. The immediate next step is the explicit adoption of the report including its timetable and funding provisions.

B. Endorse and maintain the recommendations of the PC report for implementation – In committing to the NDIS, government needs to acknowledge the specific recommendations of the PC in terms of basic construct and governance.

C. Develop and apply a purposeful risk management framework for implementation – The risk management framework must be rigorous and targeted to appropriately identify and address potential slippage of the key principles underpinning an NDIS.

D. Build sector-wide capacity to facilitate change – A focus on building the capacity of the system, support organisations, as well as individuals and their families, will contribute to the realisation of choice for the individual and broader facilitation. This will require the development and introduction of various tools and mechanisms to guide change.

### 3. Actively pursue system and cultural change ➔ INCLUSION

A well-functioning NDIS will facilitate some of the change necessary, but fundamental change in mainstream services, infrastructure and cultural mores is a job for all governments. In order to achieve true social inclusion and citizenhood for people with a disability, a whole-of-government approach is required.

In promoting such an endeavour, transfer of information and knowledge capital about the size of inequity will be needed.

### 4. Begin and continue a process of outcome monitoring and public reporting ➔ RESULTS

Government and the National Disability Insurance Agency (NDIA) have a significant role in assuring outcomes through building and implementing a strong monitoring and evaluation framework within the governance model recommended by the PC. This will involve transparent reporting against proxy measures, but more importantly, changes in outcomes at the individual level and shifts at the community level.

# The story so far

*The historical experience of people with a disability illuminates the current state of disability care and support in Australia. Despite significant changes along the way, there has been limited improvement. In fact, Australia is among the worst performers when it comes to key indicators such as employment and disadvantage of people with a disability. Further fuelling this poor performance are societal attitudes towards people with a disability, which have evolved only slowly over time.*

The treatment of people with disabilities as second–class citizens over the ages, even their outright exclusion, serves to further contextualise the current situation of disadvantage among this diverse subset of our population.

Attitudes and cultural representations that go back to Greece and Rome are still threaded throughout our society. Societal views towards people with a disability over the centuries were further driven by the development of negative associations – 'evil', 'to be pitied', 'unproductive', 'dependent', 'a drain on society'.

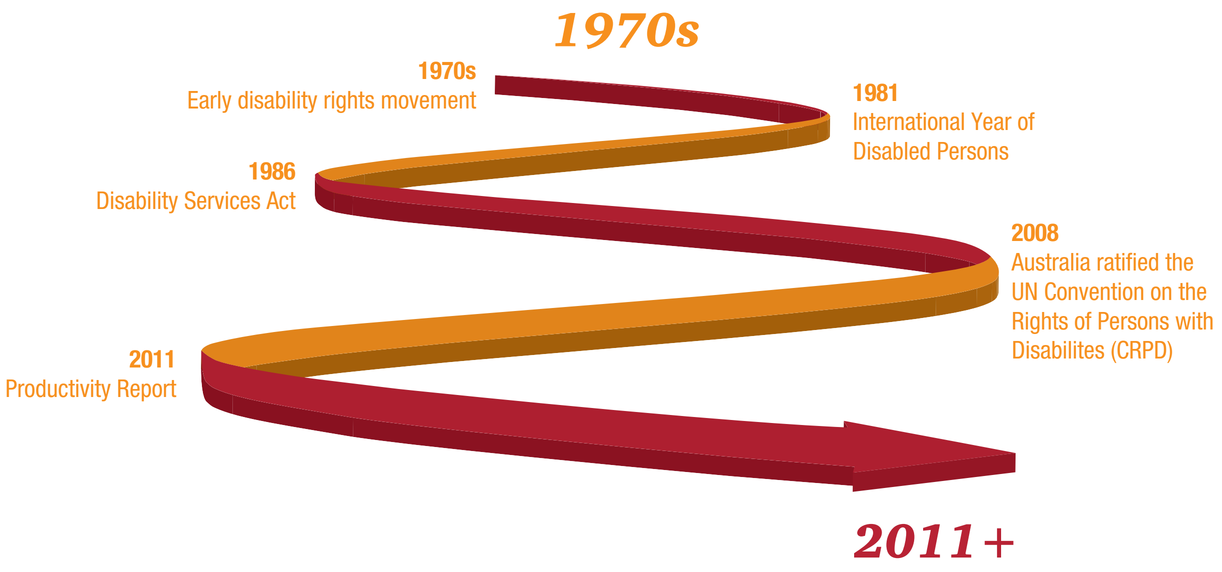
Despite these attitudes, there was often acceptance and inclusion at the family and local level. This continues into the modern day, with informal supports being the principal contributors in the disability care and support system.

## The 20th century – significant change, marginal improvement

As recently as forty years ago, people with a severe disability were still largely separated from the community – and invisible to the community. Typically they either died young, were supported under extreme hardship by their families, or spent their life in institutions with names such as *Blind, Deaf and Dumb Asylum, Home for the Incurables, Destitute Asylum, or Kew Idiot Asylum.*

Largely stimulated by the philosophy of normalisation in the 1970s and the early disability rights movement, a number of diverse academic and political trends accelerated the movement toward deinstitutionalisation and a 'rights-based' approach to disability. The emphasis shifted from dependence to independence as people with a disability sought a political voice and became active against social forces seen as depriving people living with a disability of their human rights.

From the mid-1980s, most Western countries including Australia enacted legislation which sought to address issues of social injustice and discrimination against people with a disability. The legislation also embraced the conceptual shift from disability being seen as an individualised 'medical problem' to a social problem and the failure of society to adapt and accommodate to people with disabilities. Thus the problem became one of redressing the social inclusion of people with disabilities rather than changing their individual characteristics or behaviour. In other words, the social model of disability.



In Australia, these policy forces culminated in 1986 with the passage of the Disability Services Act. However, these policies have raised expectations without providing solutions. We are now one of the poorest performers in disability support among comparable OECD jurisdictions. The employment rate for working-age people with a disability in Australia has declined since the mid-1990s and during the mid-2000s.[19] Australia is ranked 21st out of 29 OECD countries.[20] If nothing is done, Australia's performance will not only grow relatively worse, but the impacts of our poor performance may affect our international competitiveness. Australia's position will be a particularly vulnerable one as it seeks to fulfil its agreements as a foundation signatory to the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

To be successful our strategies require accompanying changes to the funding and structure of disability support services. The most important funding and policy instrument has been the CSTDA (Commonwealth State and Territory Disability Agreement), now known as the NDA (National Disability Agreement). The essential story of the CSTDA from the first agreement in 1992 to the NDA in 2009 has been one of creeping acceptance by the states that the fiscal task of meeting unmet need for disability is beyond their resources, and a deepening Commonwealth involvement in every aspect of disability policy.

Subsequent sections of this paper consider the case for fundamental change in the support framework for people with a disability for which the NDIS will be a catalyst in moving towards better outcomes for people with a disability in Australia.

Some of the key milestones along the way to an insurance-type approach have been:

- In 2005, a report[21] to insurance ministers considering tort law reform introduced the viability of and options for long-term care arrangements for the catastrophically injured
- In 2006 and 2007, the NSW Lifetime Care and Support (LTCS) scheme came into effect, first for minors and then for all persons
- The UN CRPD was signed in March 2007 and ratified for Australia in July 2008
- In 2007, the Senate report into the funding and operation of the CSTDA was released and recommended the development of a National Disability Strategy
- In 2008, the idea for an NDIS was raised at the 2020 Summit. This was shortly followed by the establishment of the Disability Investment Group
- In 2009, the National People with Disabilities and Carer Council released the Shut Out report, describing the experience of people with disabilities and their families
- In 2009, the Senate referred the matter of access to planning options and services for people with a disability to the Community Affairs References Committee for inquiry
- In 2009, the PC was asked to investigate the feasibility of an NDIS, considering design, administration, financing and implementation.

The prospect of an NDIS and the accompanying sector campaign[22, 23] have spotlighted the issues for people with a disability. However, far more than a funding solution is needed to achieve the outcomes desired.

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[19] OECD. (2009). Sickness, Disability and Work: Keeping on Track in the economic downturn – Background Paper.

[20] OECD. (2010). Sickness, Disability and Work: Breaking the Barriers - A Synthesis of Findings across OECD Countries; cited in Appendix K The disability support pension. Productivity Commission Inquiry Report. No. 54, 31 July 2011.

[21] PricewaterhouseCoopers (PwC). (2005). Actuarial Analysis on Long Term Care for the Catastrophically Injured.

[22] http://everyaustraliancounts.com.au/

[23] http://australiansmadashell.com.au/

# The problem

*The current environment – meaning the system and societal attitudes – does not offer people with a disability the same opportunities it does other Australians; it is disjointed, inequitable and massively underfunded. People with a disability continually experience poor results in welfare and levels of participation. The case for change straddles policy and funding – the solution needs to see these elements aligned with each other, and with practical implementation and cultural impact.*

> *We are now back to lobbying for a package, and have been told we will only access one if we go into crisis or relinquish care. I used to wonder how parents could do that, but I see it's the only option. (Mad as Hell, sub. 153, p. 8)*

## The policy context: The impact of disability in Australia

Australians with a severe disability and their families have sub-standard outcomes on every indicator of community participation and wellbeing:[24]

- Substantially reduced opportunity for participation in activities outside the home – as low as one-tenth when compared with the Australian population
- Half progress past year 10 at school, compared with 80% in the general population[25]
- 31% participation in the labour force compared with 83% for people without a disability
- Two-thirds earn less than $320 per week compared with one-third of the general population
- Many times more likely to live in public housing and more than 6,500 aged under 65 live in aged care homes[26]
- Only 20% report having their support needs for core activities (mobility, self-care, communication) fully met by the formal support system[27]
- Waiting times of up to two years for a basic wheelchair or therapy, or up to 10 years or more for supported accommodation[28]
- Carers have the lowest level of wellbeing of any group studied.[29]

In the worst cases, ageing carers (usually mothers) are forced to relinquish the care of (ie abandon) their adult child as the last resort to obtaining care for their child before they die. Samples of submissions to the PC are presented in this section.[30]

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[24] We refer to people under 65 years with a profound or severe core activity limitation, of which there are almost 1.2 million (All examples and data are from Chapter 2, PC report).

[25] ABS. (2010d). Disability, Ageing and Carers, Australia, 2009, Basic CURF, Cat. no. 4430.0.30.002, Commonwealth of Australia, Canberra.

[26] YPINH (Young People in Nursing Homes). (2011). Statistics. www.ypinh.org.au/index.php/Statistics.html.

[27] ABS. (2010d). Disability, Ageing and Carers, Australia, 2009, Basic CURF, Cat. no. 4430.0.30.002, Commonwealth of Australia, Canberra.

[28] Women with Disabilities WA Inc. (2011). Submission to the Productivity Commission on an NDIS May 2011. Submission 1009.

[29] Cummins, R. A., Hughes, J., Tomyn, A., Gibson, A., Woerner, J. and Lai, L. (2007). The wellbeing of Australians: carer health and wellbeing. Report 17.1. Australian Centre on Quality of Life and School of Psychology, Deakin University, Melbourne.

[30] The selection of submission testimony is taken from Box 1 and Box 2.1 of the 2011 Productivity Commission report, p. 8 and p. 133.

*The only way to get help, we were told, was to relinquish our little girl to DoCS (community services). Eventually we could not cope and found ourselves in a world where authorities find it hard to distinguish loving parents from those who abuse their child. It was wrong. (Mad as Hell, sub. 153, p. 7)*

*The regularity with which I meet parents with murder - suicide ideation as they have been unable to find adequate help for their child is both alarming, but also a marker of the failure of coordination of any service. (personal submission, senior psychiatrist)*

## Policy: The National Disability Strategy

### *The vision for now and the future*

The National Disability Strategy 2010 – 2020[31] is a 10-year commitment by all levels of government to focus on supporting people living with a disability to participate in life on equal footing with all other Australians; to have the opportunity to fully realise their potential, and to feel empowered to follow their aspirations. The COAG endorsed the National Disability Strategy on 13 February 2011 after nationwide public consultation. The National Disability Strategy adopts a nationally unified and consistent approach that has at its core the goal of improving the lived experiences of people with a disability, their families and carers in Australia.

The National Disability Strategy is underpinned by three key platforms:

- The human rights imperative – people with a disability must be afforded the same rights as all other Australians
- The social imperative – inclusion and participation in everyday life for people living with a disability is paramount. Everyone is part of the solution and this involves changing attitudes
- The economic imperative – people with a disability need to be supported and encouraged to contribute through workforce participation and other productive avenues.

The National Disability Strategy acknowledges the importance of collaboration across government, industry and community to strengthen the disability sector, which includes recognition that people living with a disability cannot participate in and enjoy all aspects of life or be fully included, solely within the remit of the specialist disability service system. Rather, community and mainstream services need to be accessible to all and attuned to the depth of diversity in our society, which includes people with a disability.

> *"An inclusive Australian society that enables people with disability to fulfil their potential as equal citizens."*[32]

Highlighted in the National Disability Strategy is the need for leadership at all levels in order to drive a cultural shift in societal attitudes – people with a disability are a valuable part of our society, with the capacity to contribute socially and economically.

While the National Disability Strategy is not yet being used as a key policy vehicle, this may change with the development of key indicators to measure the achievement of the six priority outcomes over time.

However, history has demonstrated that frameworks of policy, strategy and principles are in and of themselves not enough to bring about significant change or reform, as was the case with the disability services legislation in 1986.

> *It is critical that the investment in and potential of the various policy platforms – ie the National Disability Strategy, UN CRPD and other applicable policy frameworks – are complemented by sound funding and governance, which delivers a means of assessing need and providing supports.*

## Funding: A core community responsibility

From a financial perspective, the need for change is simple: it is not realistic to expect sufficient sustained support from those who have borne this 'cost' previously. The 'contributors' have been:

- **people with a disability**, who have contributed in lost life years through premature death and in loss of amenity due to the handicaps imposed by society while they were alive
- **families**, who have contributed through providing the major support safety net
- finally, the overall **community**, which is called on to contribute more and more through the efforts of non-government organisations and, increasingly, through state government taxation revenue.

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[31] COAG. (2011). National Disability Strategy 2010 – 2020. Commonwealth of Australia, p. 22.

[32] Ibid.

### Firstly, people with a disability themselves:

Advancements in medicine are increasingly providing longer lives for people with a disability – and society has determined that increasingly vigorous efforts be made to keep alive those with very severe disability.

Australia has agreed through ratifying the UN CRPD that the lives of these men and women living with a disability are valued and they should be afforded full participation in society. This obligation then becomes a responsibility carried by the whole of the Australian community, not individuals with a disability.

### … next, families and carers:

The Way Forward[33] reports that:

"In 2003, approximately 2.5 million people reported providing informal care to a person because of a disability or old age. Of these 2.5 million people, approximately 20 per cent (or 474,600 people), reported being the primary carer of a person with a disability. Of these carers, 187,500 (40 per cent) had a disability themselves. Using assumptions on average hours of care per week for primary and non-primary carers, there were approximately 643,000 full-time equivalent informal carers in Australia in 2003, providing an estimated 24.4 million hours of care per week.

Primary carers are likely to be in the poorest two-fifths of all households and 55 per cent receive income support as their main source of cash income. Most primary carers (71 per cent) are women."

PwC estimates that currently at least 80% of the total support need of people with a disability is provided by this so-called 'informal care' network of families and friends. Moreover, the availability of informal care is declining due to a combination of ageing carers, reducing 'stock' of family support, and plain burn-out.[34]

Continued support by families is unsustainable at the levels relied on by our community in the past century. Moreover, the decline in this support has a leverage effect on our next funder.

### … state governments:

The majority of support hours for people with disability are provided informally.

Due to the significant reliance on informal care, a small reduction in informal care translates to a larger increase in the demand for formal care – a multiplied effect.

State governments are faced with growth funding of up to 10% per annum for disability due to the pressures articulated above combined with other pressures such as population growth and ageing. Between 2004–05 and 2009–10 Australia has experienced 47% growth in the number of people using disability support services.[35] Over the five-year period, this represents an 8% per annum compound growth rate. State governments must choose one of two options:

- Find the extra funding. As noted in the Productivity Commission's report, the states' revenue base is unlikely to be able to achieve this level of increase, particularly considering the substantial increases expected in health and infrastructure funding
- Provide disability support services only to those most in need. In effect, this is what had been happening until the recent recognition of the 'problem of disability', and that it creates the 'death spiral effect'.

*Consider the following algorithm presented by the New South Wales Government as part of its Stronger Together 2 proposals:*[36]

*A 10% reduction in informal care over six years (1.6% per year) translates to increased demand on formal care of 45% over the six years, or over 7% per year.*

*This scenario does not take into account any increase in need.*

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[33] Report of the Disability Investment Group, October 2009. Includes data and findings from ABS Survey of Disability, Ageing and Carers 2003.Cat no 4430.0; and PricewaterhouseCoopers, National Disability Insurance Scheme, 2008, p. 32.

[34] Australian Institute of Family Studies (AIFS). (2008). The nature and impact of caring for family members with a disability in Australia, Research report no. 16, AIFS, Melbourne.

[35] AIHW. (2011). Disability support services 2009–10: report on services provided under the National Disability Agreement. Disability series. Cat. no. DIS 59. Canberra: AIHW.

[36] PricewaterhouseCoopers. (2011). Stronger Together: A new direction for disability services in NSW. The second phase (2011-2016). A sustainable approach to meeting increasing demand.

The death spiral effect emerges when rationed funds are used only in 'crisis situations'. This typically happens when an ageing parent (often a mother in her seventies or eighties) is no longer able to care for her child with a disability. The child may be an adult son in his forties or fifties who has been supported at home for his whole life. In recent years, the mother may have been trying to get help, but lack of funding has meant she has to hang on as the sole help provider – until she can't.

A crisis situation then develops and a supported accommodation place must be found – a so-called 'emergency response' or similar. These responses are expensive, and they siphon funds from lower-level – often respite – support to other ageing or struggling carers (it is estimated that one emergency response can use up the funds of 10 lower-level respite packages). The situation then snowballs, and more families are forced into crisis.

Put simply, the macro effect of these snowballing crises on a limited budget means that fewer and fewer services can be provided, and that the average cost of services must increase until the system is supporting nothing but a fixed number of high-end support places.

### … and finally, non-government organisations:

Increasingly, non-government organisations (NGOs) will be relied upon to develop innovative support models in a world of person-centred, individual funding, and to assist in building community capacity and in developing the skills of their workforce.

NGOs have been able to successfully mobilise community capacity to support disability-related supports. Part of this activity has been successfully raising funds from the community to value-add to services. However, the PC estimates that an additional $6.5 billion is required to provide people with the necessary supports. It would be extremely difficult for NGOs to raise such funds from the community and it would require a substantial and sustained increase in community giving.

## *The need for a new funding model*

What is needed is a funding and governance model that:

- is national
- is based on an estimate of the support need of people with a disability
- supports and funds the need in a responsible way
- encourages active participation by people with a disability
- supports and encourages the ongoing efforts of carers and NGOs
- manages risk and cost escalation.

The funding and governance solution proposed by the PC is the **National Disability Insurance Scheme**. This model transparently puts into effect Australia's ratification of the UN CRPD and at the same time assumes the responsibility for our whole society to meet this promise, rather than persisting with a small number of unsustainable options. The NDIS is needed as a means to implement and deliver on the National Disability Strategy, the UN CRPD and other policy vehicles. In thinking about the intersections of the NDIS with broader policy settings, it is vital that a focus on policy effort continue alongside this rigorous funding and governance solution through reinvestment of surpluses.

There is a clear commitment from government to the National Disability Strategy, and bipartisan support for the funding and governance model proposed by the PC.

We now need a goal to work towards for people with a disability – a 10-year horizon to deliver real outcomes.

## The value of reform

*As noted above, the PC inquiry into the disability system in Australia found the system to be fragmented, inefficient and underfunded. Federal and state/territory governments have increased funding inconsistently and on an ad hoc basis, meaning funding is uncertain and volatile (see Figure 14.1 of the PC report). There are long-term economic and fiscal benefits that can be gained from increased and consistent funding.*

### Scenario 1

*This is the 'do nothing' scenario – funding increases in line with GDP only. In the current system, which has significant unmet need, funding is funnelled to high-cost 'crisis' situations. With no additional funding, the only way to fund these high-cost crises is to cut funding to less expensive early intervention and respite programs. This in turn increases the risk of more crises as people lose the low-level support that they rely on. Ultimately, the service system provides a small number of high-cost places and the demand for crisis response will lead to increases in expenditure and poor social outcomes.*

### Scenario 2

*This scenario assumes some increases to funding and improvements in the support system. It is based on the NSW Stronger Together 2 (ST2) proposal. ST2 focuses on early intervention and prevention and moving the system to a 'person-centred' system rather than the current service-based system. These reforms provide assistance to far more people than Scenario 1, avoid crisis situations and change the expected life pathways of people with a disability. This scenario leads to better outcomes for the individual (eg increased employment opportunities and community participation) and reduced cost to government.*

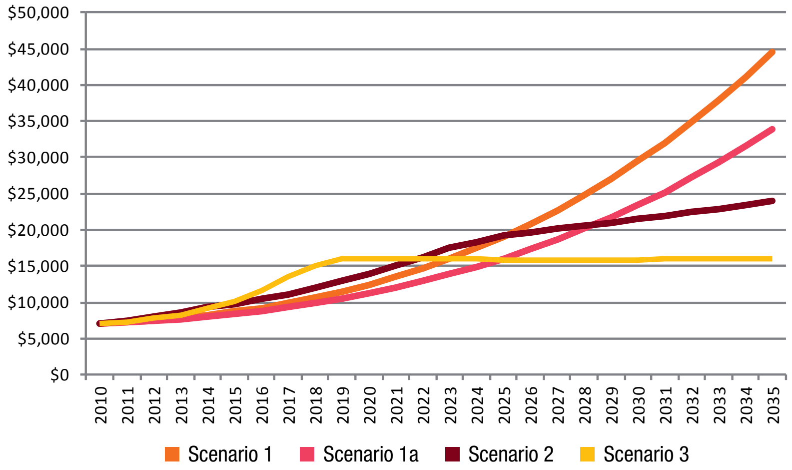
### Scenario 3

*This scenario assumes the introduction of the NDIS and supplementary reforms. The strong governance and monitoring framework that underpins the insurance model will result in improved outcomes for people with a disability and reduced expenditure over time. In particular, it will produce increased employment for both people with a disability and their carers, likely reductions in 'blocked' hospital beds and hospitalisations, and reduced rates of incarceration. People with disabilities will be less reliant on high-cost, 24/7 supported accommodation and will become more independent through early intervention programs.*

*The estimated cash flows for the three scenarios are presented in Figure 1 below.*

- *It is estimated that introducing the NDIS (scenario 3) is the most cost-effective way of meeting the needs of people with a disability over the long term. While the upfront cost is higher, the benefits outweigh these upfront costs over time*
- *Not investing in the disability system (scenarios 1 and 1a) results in higher costs over the long term due to crises (using alternate assumptions) and also results in unacceptable social outcomes*
- *With continued effort, ST2 (scenario 2) will ultimately result in positive social outcomes and a positive economic outcome. However, the economic outcome is not as good as under the NDIS, as the benefits will take longer to realise and reforms are not as comprehensive.*

**Figure 1: Estimated cash flows under the various scenarios ($m)***



*Note: Cash flows were adjusted for growth in real GDP.

# *A 10-year horizon – Principles for disability in Australia*

*Australia now has the potential to fundamentally change the disability experience through a funding, governance and outcome system. The NDIS is a mechanism that will bring about efficiencies, rearrange roles and change the control hierarchy to promote choice and individuality. This chapter focuses on a 10-year vision for disability in Australia, underpinned by four basic principles that highlight the critical intersection between implementing an NDIS and improving the capacity of the system to deliver a wide range of rights and freedoms, as well as realising improved economic outcomes. At the forefront of this plan is achieving better outcomes for people with a disability and their families.*

## What is the vision for 2020?

Within a decade, people with a disability will be viewed and engaged with as fellow contributing citizens, afforded the same rights and opportunities as all other Australians. Within this 10-year horizon, people with a disability and their families will receive the supports they need to pursue their goals and interests and participate fully in life.

This vision needs to be underpinned by a **social model** of disability, whereby the extent or nature of disability experienced by people is predominantly linked to barriers that exist in society. In other words, the achievement of the outcome will depend on the degree to which society supports (or inhibits) the social, economic and cultural participation of the individual (through citizenhood and accessible community infrastructure).

The optimal approach for managing reform in disability involves adopting an insurance-based risk management framework, as distinct from the current welfare model. Tapping into community potential and cultural impact is a key piece of the puzzle. This means that large-scale investment in branding and awareness campaigns will be necessary.

If the best approach is not adopted from the start, the next five to 10 years may not be as transformative for disability in Australia as envisaged.

## *Real outcomes for people with a disability*

As a first step to realising the 10-year vision, clear outcomes need to be identified and committed to. The success and measure of an NDIS, alongside disability services reform, will be the realisation of outcomes for the person with a disability. Changes in policy, funding, structure and support delivery need to be brought about in a manner that is sensitive to the needs and wants of the individual and must achieve real outcomes, not just 'throughput'. These outcomes are well contained within a quality of life framework[37] such as the one shown below in Figure 2.

The eight outcomes/quality of life domains essentially pinpoint what is needed at the broad level for people with a disability to lead enriched lives, despite their level of impairment, function or capacity. They are universally relevant.

The key theme of this paper is 'achieving better outcomes for people with a disability and their families'. However, achieving these outcomes will be contingent on another theme in this paper – that of cultural and community change in order to affect a real shift in both the disability and mainstream systems. This goes beyond people living with a disability; it is about all Australians. There is a need to build community capacity so that available supports and natural relationships are strengthened. This will produce an efficiency flow-on effect that reduces the need for intensive and potentially intrusive formal support.

## Figure 2: Quality of life domains

| Interpersonal relations | Physical wellbeing | Self-determination | Social inclusion | Emotional wellbeing | Material wellbeing | Personal development | Rights |
|---|---|---|---|---|---|---|---|
| Affiliations | Health care | Choice | Natural supports | Safety | Ownership | Education and habilitation | Privacy |
| Affection | Mobility | Personal control | Integrated environments | Stable and predictable environments | Possessions | Purposive activities | Ownership |
| Friendships | Wellness | Decision | Participation | Positive feedback | Employment | Assistive technology | Due process |
| Intimacy | Nutrition | Personal goals | Barrier – free environments | | | | |
| Interactions | | | | | | | |

Source: Schalock, et al, 2002.

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[37] Schalock R. L., Brown I., Brown R., Cummins R. A., Felce, D., Matikka L., Keith K. D. & Parmenter T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Results of an international panel of experts. Mental Retardation, 40(6), p. 457–470.

In conjunction with community level change and responsibility, accessible mainstream services, accountable governments and appropriate funding are key elements for moving beyond simple rhetoric and achieving real improvement in the disability experience. The figure below illustrates some of these elements and the way in which they could interact to bring about citizenhood, economic and social return, and basic rights to the individual.

The complexity of the system and the multiple dimensions contributing to key outcomes for the individual and society are depicted in Figure 3. While the NDIS has a central role in linking the key stakeholders and elements with the individual, societal and system outcomes, it is important to highlight that effective interaction among the elements and stakeholders must be realised in conjunction with the establishment of the NDIS. The NDIS is not just a funding vehicle; it is a means to promote inclusion, capacity building and accessibility in the broader community.

In order to align the design and implementation of a scheme on this scale of change with the attainment of meaningful outcomes for the individual and society, it will be prudent to adopt a principles-based approach, which can serve as a checklist to guide the change.

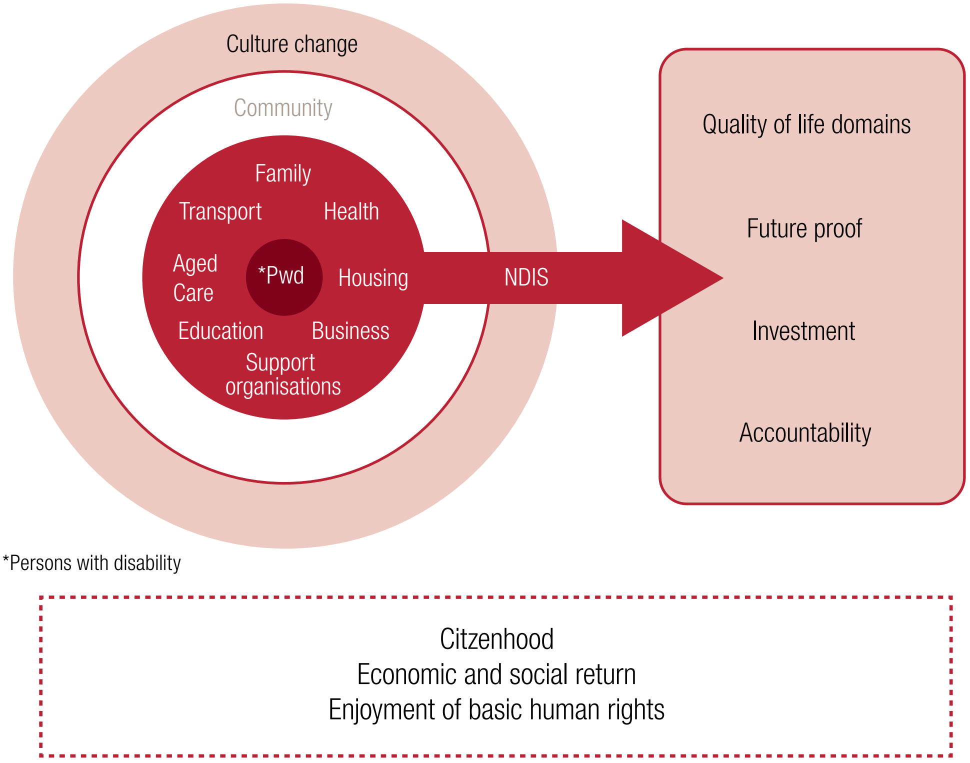
## Guiding change

### *Overarching principles*

Reflecting on the story so far and the case for change we propose four principles that should underpin a 10-year plan to change disability in Australia and achieve the key outcomes represented by the quality of life domains identified above:

1. People with a disability have equal rights
2. Supports are needed to allow people with a disability to exercise their rights
3. Individuals with a disability should have choice in prescribing their access needs
4. Cultural, systemic and environmental obstacles to access and participation for people with a disability should be removed.

**Figure 3: Key Interactions for disability**



Source: Adapted from David Barbagallo, 2011.

### People with a disability have equal rights

While the recognition of equal rights among peoples of all races, colours and creeds is now near universally established, those with a disability still struggle on the margins of recognition. By being among the first countries to ratify the UN CRPD, Australia has recognised that equal rights extend to people with a disability. It is about **fairness**.

### Supports are needed to allow people with a disability to exercise their rights

Infrastructure, social networks and culture have always been built with the assumption they will be used by able-bodied people. People with a disability have been denied access, hidden and ignored. They and their families are arguably the most disadvantaged of all Australians across much of our society.

If people with a disability are to exercise their human rights, they need a range of facilitators to negotiate the parts of the world that remain inaccessible. For Australia, the first step in building these supports has been delivered in the government's acceptance of the PC's report proposing an NDIS, which greatly enhances funding for people with a disability and recommends a support and governance framework for this funding to achieve its maximum impact.

This is about **facilitation.**

### Individuals with a disability should have choice in prescribing their access needs

A critical component of this framework is the dismantling of rationed, block-funded government purchasing of a narrowly defined suite of services.

Funds are to be transferred to individuals with a disability, allowing them to define their values and work towards a life of participation in the community, like other Australians. They will have the purchasing power to choose what their supports look like.

The market of support organisations needs to respond to this vision by building the skills and flexibility that will allow them to evolve from service providers to agents of outcomes – providing the fulfilment of rights and **choice**.

### Cultural, systemic and environmental obstacles to access and participation for people with a disability should be removed

One limiting factor upon the potential for change is the current obstacles people with a disability face when seeking access to education, employment, health, transport and housing. Individual rights, choice and purchasing power will not of themselves guarantee citizenhood.

To promote social participation and minimise the impact of disability, Australian governments and the community need to work together to systematically facilitate access to these mainstream services for all people. In other words, **inclusion**.

## *Benefits of change*

While at first glance these principles seem self-evident, the current system is a very long way from satisfying them, and the path to achievement will be long and difficult. It will require a shift in attitude from prescribed service delivery to facilitated community participation. It will require a shift in expectation from passive receipt of services to active citizenhood.[38]

Alongside this shift exists the potential to realise significant benefits for a wide range of stakeholders – firstly, people with a disability, their families and carers; but also support organisations, workers, states and territories, the federal government and wider Australian society.

The benefits of change and reform for people with a disability and their families and for Australia as a whole are clearly articulated in the PC report.

Substantial economic benefits will be generated over the next 10 years and beyond. These are highlighted below.

### Improved wellbeing for people with a disability and informal carers

The potential gains through an NDIS need to be considered in light of the degree of current unmet need and the potential to narrow this gap for people with a disability and their carers.

### Increased employment participation by carers

The PC indicates that employment of carers is also likely to increase. Analysis of the 2009 Survey of Disability, Ageing and Carers (SDAC) suggests that around 80,000 carers could either enter the workforce or increase their number of hours worked.[39]

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[38] Williams, R. (2010). Model of citizenhood support – Discussion Paper. Julia Farr Association.

[39] PC. (2011). Disability Care and Support. Productivity Commission Inquiry Report. No. 54, 31 July 2011.

### Fiscal gains associated with greater participation

Increasing the number of carers in the workforce or their number of hours worked, as stated above, would lead to additional GDP of $1.5 billion per annum.[40] However, the long-term benefits that would accrue are immense, as such an increase would take some time.

### Increased employment participation by people living with disability

Currently, the employment rate of people with disabilities in Australia is low when compared with the OECD average. People with a disability in Australia are only half (50%) as likely to be employed compared with people without a disability.[41] In comparison:

- For the OECD the relativity is 60%
- Considering the top eight OECD countries, the relativity is closer to 70%.[42]

The PC estimates that the NDIS and DSP reforms will lead to an additional 320,000 people with a disability employed in 2050.[43] However, if Australia realised employment ratios comparable to the top eight OECD countries, this could be higher – an additional 370,000.[44]

Australia could achieve additional GDP of almost $50 billion (a further 1.4% contribution to GDP) in 2050 if Australia moved into the top eight OECD countries in employing people with a disability. This would require productivity of 80% of the average to be achieved and people with a disability to work 80% of the average FTE worker.[45]

More conservative estimates, taking into account the NDIS and DSP reforms, would still yield additional GDP of $31 billion in 2050 (a further 0.88% contribution to GDP).[46] This assumes that the productivity of people with a disability is approximately 60% that of the national average and that they would be working part-time at 60% of an FTE worker.

### Efficiency gains in the disability sector and savings to other government services

The number of service users under the NDA increased by 47% over the last five years,[47] indicating strong growth in demand for services. Nevertheless, there is currently inefficiency in the administration and provision of services due to rigid block funding and contractual arrangements. The PC report promotes greater competition among service providers and is underpinned by insurance principles. These attributes will lead to better use of resources.

The way in which resources are currently applied in the disability sector also has flow-on effects to other government services. For example, people with disability under the age of 65 are inappropriately residing in hospitals due to limited community-based supports or unsuitable accommodation – ‘blocked beds’. The estimated annual cost to the health system of these blocked beds is between $38 million and $84 million.[48]

Similarly, just under 30,000[49] people reside in prisons in Australia at an annual cost of around $100,000 per annum per person.[50] Large proportions of people in prisons have an intellectual disability, an acquired brain injury or a mental health condition.

Significant reform in the disability system could lead to reduced incarceration. If the number of prisoners in Australia decreased by 10%, this would result in savings of approximately $300 million per annum to the prison system.[51]

The disability support and early intervention programs to achieve these outcomes are able to be provided at far more modest unit costs and will achieve far better outcomes.

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[40] PC, 2011, op.cit.

[41] OECD. (2010). Sickness, Disability and Work: Breaking the Barriers - A Synthesis of Findings across OECD Countries.

[42] Ibid.

[43] PC, 2011, op.cit.

[44] OECD, 2010, op.cit, PwC calculations.

[45] Ibid.

[46] PC, 2011, op.cit.

[47] AIHW. (2011). Disability support services 2009–10: report on services provided under the National Disability Agreement. Disability series. Cat. no. DIS 59. Canberra: AIHW.

[48] Department of Health data (Unpublished); cited in PC. (2011). Disability Care and Support. Productivity Commission Inquiry Report. No. 54, 31 July 2011. p. 143.

[49] ABS. (2010). Prisoners in Australia, 2010. Cat. no. 4517.0.

[50] Steering Committee for the Review of Government Service Provision (SCRGSP). (2011). Report on Government Services 2011. Productivity Commission, Canberra.

[51] PwC calculations, based on ABS, 2010, op.cit. and ibid.

While outcomes measurement has typically been absent within the Australian disability sector, the time has come for this to change. There is now a potential mechanism to make this happen.

## *How will we know when we get there?*

Monitoring, review and evaluation of the 10-year plan is critical. This will not only involve reporting against key input, process and output measures, but more importantly, future reporting will need to reflect changes in outcomes for people with disability – ie outcomes in employment, education and social participation.

This means:

- key indicators across the areas that align with quality of life domains, which will serve as the basis for identifying areas of need, allocating funding and resources, and monitoring change over time
- consistency with international measures and indicators used by our OECD counterparts to track progress and gauge our standing in the broader international context.

> *"The scheme should ensure ongoing rigorous independent monitoring of individual outcomes against benchmarks of engagement, social inclusion and quality of life..."*[52]

The NDIS is designed as an insurance scheme with a rigorous framework for collecting and using data within a governance framework. It will be a powerful social engineering tool. For example, the NDIA could provide a means to quantify unmet need in mainstream systems such as transport, education and housing.

> *"... it is of critical importance that the national scheme considers an authentic outcomes measurement framework that captures the degree of impact on disability funding in people's lives."*[53]

In addition to evaluating change in outcomes at the individual level, measuring changes in culture and community attitudes will be required to gauge progress.

Upfront effort in designing the monitoring and evaluation framework with key indicators and outcomes measures will be critical in appropriately quantifying need. By doing this, the Scheme and the system as a whole will be better informed and equipped to meet the needs of people with a disability in a timely and sustainable manner.

### *Box 1: Matt's story*

*Matt was diagnosed at a young age, initially with developmental delay and severe language disorder, and soon after with an autism spectrum disorder.*

*After his diagnosis, Matt was able to access early intervention services. Through early intervention, staff worked with the family to develop a plan, which enabled everyone involved with Matt to address his needs in a cohesive way. This was instrumental in developing Matt's skills and supporting his severe language disability so that he was able to attend his local primary school. With the help of Lifestart School Age Services, he has been able to continue his schooling in the mainstream system.*

*Matt has since left school and works part-time at Big W. He loves it. His employer reports that he is a good worker, punctual, dedicated and reliable. He has been given a permanent position on full wages, after a short time as a supported employee.*

*Early intervention paved the way for so much of Matt's success. In those early years the foundations for his learning were set and the strategies that were taught to his family have remained as the basis for supporting him through the challenges he has faced.*

*Matt and his family have come far. He has the ability to live a reasonably independent life, provide for himself, care for others, and participate in the community.*

*Matt and his family consider themselves to be very lucky.*

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[52] Bigby, C. and Fyffe, C. (2011). Response to PC Draft Report: Disability Care and Support. April 2011. Submission 933, p. 10.

[53] Williams, R. (2010). Submission made by Julia Farr Association: Disability Care and Support. Julia Farr Association, 24 August 2010. Submission 494, p. 55.

# An inclusive Australia: What needs to change

*People with a disability are a diverse group within our population. The social and economic contribution they are capable of making is massively undervalued and often forgotten altogether. The PC report highlights this disturbing situation and proposes a policy and funding approach to begin to remedy the broken system through the introduction of an NDIS – championing person-centred control and enhanced funding. In considering the path to change over the next five to 10 years, this chapter discusses the implications across a range of stakeholders: individuals and their families, providers of support services, mainstream services, government, and community and informal supports.*

## Introduction

Australia needs a transformative shift not only in the way services are funded but also in the way they are delivered. The system must be built and structured around the needs of the individual, rather than system and organisational needs. We need a fundamental shift of power from organisations to individuals, who will have greater control and choice not only in the type of provider they choose but in the type of service and support.

### Implications for change across stakeholders

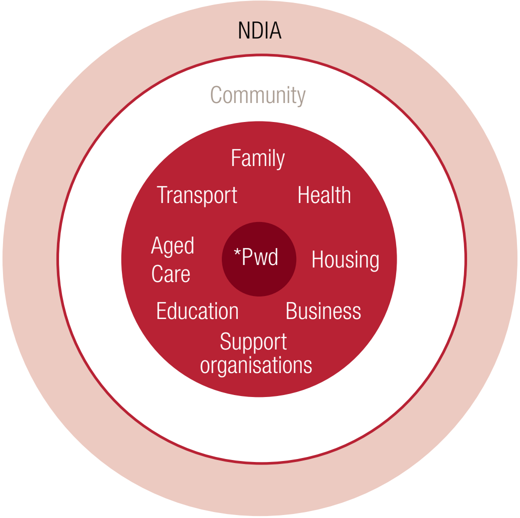
However, if real transformative impact is to be realised, a number of fundamental changes need to occur. These changes need to occur at every level of the system – from people with a disability and their families to specialist disability service providers, to mainstream service providers. The NDIS can act as a powerful driver of social and cultural change – but only if key stakeholders at every level of the system are equipped with tools and resources to successfully negotiate the change. Powerful preconditions must be met for the proposed funding and governance model to radically improve the lives of people with a disability and their families.

The changes across stakeholders described in subsequent sections can be summed up in the notion of capacity building. The capacity of people with a disability, their families, providers of support services, mainstream service providers, and the community as a whole must be carefully built so each level is equipped to meet the diverse support needs required.

> *The true measure of the success of system change will be how well it empowers all people with a disability, not simply those who already possess the skills and resources necessary to manage individualised and self-directed funding.*

Successful change will require all parts of the system and all key players to work together. This is illustrated below.

**Figure 4: Key elements and stakeholders**



*Persons with disability

## What if change does not occur?

If these changes do not occur there is a risk that the impact of the NDIS will be limited and it will fail to achieve its transformational vision.

For example, if people with a disability are not provided with quality, timely, evidence-based information to inform their choices and a supported to exercise meaningful choice, there is a risk they will simply revert to using services they are already familiar with, regardless of how well the service meets their expressed needs or how happy and satisfied they are with the service. If people are not enabled to make meaningful choices and provided with information and resources with which to make them, then the notion of 'choice' becomes empty rhetoric and the system will fail to live up to its transformative potential. The NDIS will then simply become a funding mechanism rather than a powerful driver of systemic and cultural change.

# Individuals living with disability

## *The challenge*

As noted by the PC, the current disability system is "underfunded, unfair, fragmented and inefficient, and gives people with a disability little choice".

The system has been built around a view of people with a disability as grateful recipients of charity rather than potentially empowered consumers capable of choosing what works best for them. The system has long historical roots in a paternalistic 'professionals know best' approach. In a highly rationed system there is obviously less capacity for innovation. In addition, the ability to respond to people's needs in creative ways diminishes significantly once they reach crisis.

As a result, there are very few people with a disability who have any experience in exercising truly meaningful choice. The current environment does not empower individuals to exercise choice. Similarly, the system is a primary barrier to specialist support organisations being able to provide enough choice. While a number of support organisations have tried to champion person-centred approaches, these efforts are often hindered by system limitations.

Overseas experience with self-directed funding suggests some people will wholeheartedly embrace the opportunity and will already possess the experience and resources necessary to make the system work for them. Others will require additional and sometimes significant support and resources in order to make meaningful choices. This is particularly true for people with a cognitive impairment who may only have had very limited control over the direction of their own lives, and for whom personal independence is an unattainable dream rather than a realistic option.

Typical models of case management, support and service delivery often do not seek to genuinely understand the needs and aspirations of the individual, but rather use a menu-driven program response.

Our system needs to make available to people with a disability all necessary and appropriate supports, options and opportunities to firstly articulate their values, and then to enable them to live a life defined by these values. This involves understanding what that means to the individual and thinking outside the 'traditional' box.

It is about **choice** and **opportunity.**

## *Moving forward – "... the dream of a meaningful life: ordinary or extraordinary"*

The greater choice and flexibility offered by the NDIS presents enormous opportunities to empower people with a disability. We have the potential for a revolutionary change – to provide the means for individuals to exercise their rights, move away from the welfare model of service delivery and engage with the mainstream culture.

In order for a disability care and support system to work for each individual, it needs to enable the person living with disability to be at the centre of the system. To do so the system must focus on the person and what makes them an individual.

### Social model of disability: Individual needs

Submissions to the Shut Out consultation report highlighted the ever-present stereotypes and misconceptions that serve as reference points upon which society bases its perceptions, views and behaviours.[54] Stereotypes of people living with disability are a key barrier to social inclusion, participation, and access to appropriate supports and services.

> *"People are disabled by society, not just by their bodies."*[55]

> *"... one client who presented with mobility impairment was provided with a mobility scooter that, despite being a good option for long distance travels in the community, this scooter was not only next to useless indoors it was found to create pressure areas. This shows... a general lack of understanding of client needs causing huge inefficiencies in an already overtaxed system..." (CPL, April 2011, p. 10-11).*

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[54] Australian Government. (2009). Shut Out: The experience of people with disability and their families in Australia. National Disability Strategy Consultation Report. Prepared by the National People with Disabilities and Carer Council.

[55] WHO. Ten facts on disability. June 2011 http://www.who.int/features/factfiles/disability/en/. [Accessed on 06/07/11].

## *Box 2: Nick's story – part 1*

*Nick is a 26 year old man who has an intellectual disability, cerebral palsy and complex health issues. He cannot speak, but he has a great deal to say and expresses himself creatively, resourcefully and effectively to those who take the time to get to know and understand him. Nick enjoys each and every day, loves and is loved by his extended family, laughs uproariously at slapstick comedy, has a circle of male friends and adores his girlfriend, Sarah. His evident pleasure in life brings joy to all those who know him.*

*With support of staff at his day program, Nick is developing everyday skills such as ordering coffee or a meal, and helping others in the community (meals on wheels, walking the dogs of local residents, serving afternoon tea to people in an aged care facility nearby). Visual communication aids optimise his independence enabling him to make choices about programs, food, and planned events. At the service where Nick has participated for 7 years he has a group of friends with whom he shares his day. They greet each other in the morning, share news, lark around, go for coffee and worry about each other if someone is unwell. Some people can speak, some cannot - but all enjoy a joke and each other's company.*

*A crucial contributor to Nick's quality of life is having something to look forward to. It can be a movie or musical stage-show, a date with Sarah, an outing with a friend, going on holiday, Christmas, Easter, birthdays - or any number of other events. It must however be something of interest and meaning for Nick, something he has played an active role in choosing - and it must be planned ahead of time as anticipation is a large component of the pleasure he derives. Exploring options with him and using pictures and simple text enable him to share his excited anticipation and, later, memories of the event with others.*

The future system needs to acknowledge the particular and diverse needs of people with disabilities and to provide assistance relevant to each person's lifestyle needs. The scheme must have the capacity to determine the level of support and assistance required to ensure that the outcome for the person with a disability is positive and meaningful in their life. This involves:

- an inclusive definition of disability to avoid people falling through the cracks. The International Classification of Functioning, Disability and Health (ICF) definition is appropriate here, with its assumptions that:
    - anyone could find themselves living with a disability to some degree
    - disability is a multidimensional concept, with interaction between the nature of the impairment and the impact on function
    - there are key facilitators and barriers that enhance or repress experience and performance (ie environmental factors)
- a need to stop seeing people with a disability as the exception to the rule or as an afterthought. People with disabilities have ordinary needs in terms of health and wellbeing, financial and social security, as well as education and training.[56] As such, they should have the right to access mainstream services and supports.

A balance of collective approaches and individualism is required in policy and practice.

The NDIS seeks to achieve this by insisting on accessible and inclusive mainstream structures that are complemented by appropriate specialist disability funding and support.

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[56] WHO & World Bank. (2011). Summary World Report on Disability.

### Expectations and self-belief

While individuals are the drivers at the core of their vision, they are very much influenced by external forces including family, peers, society and the system itself. From a young age, people are moulded by their experiences, both positive and horizon-limiting. To some degree, an individual's expectation of what they can achieve and aspire to is driven by their perceived or known capacity. Much of what anchors a person's self-belief and expectations comes through lived or observed experience.

In the context of a person living with a disability, this can be further complicated by the nature of their disability – for example, whether the a disability is physical versus cognitive, or congenital as opposed to acquired.

Whether someone is born with a disability or acquires it at a later stage in life, the key issue is the way in which societal attitudes and expectations are transferred to the individual – not at a superficial level but at an internalised level. What happens when a person with a disability internalises negative representations and interactions?

Prolonged exposure to horizon–limiting views and experiences shapes an individual's sense of self and influences their behaviour, the conduct of their lives, and their capability to recognise possibilities in life.

It will be important to challenge the limitations imposed on people living with a disability by others.

## *Box 3: Fiona's story*

*In 1981, Fiona acquired her impairment – transverse myelitis, which was deemed a non-traumatic injury and non-compensable, making it more difficult to access needed supports. Fiona was 18 years old and studying for an Arts degree at university. She had always assumed that she would get a university education and have an academic career – it was expected and important to her. However, it was difficult for Fiona to return to study and it took her several years to find her way back. She resumed university study in 1987 and completed her Bachelor of Legal Studies (Hons) in 1998.*

*One of the first barriers she experienced was the social worker who was supposed to assist her in returning to study. Fiona was given the choice of either a specialist nursing home for people with quadriplegia/paraplegia or sheltered workshop employment. Fiona explored them both. She visited the nursing home and realised immediately that it was the wrong environment. She spent about three weeks employed at the sheltered workshop. The environment was dehumanising. Her experience there did not align with her goals and dreams and persisting in this environment would only have reduced her expectations and self-belief. And so she left.*

*Fiona needed 28 hours of care a week to stay out of a nursing home environment. She worked to stay out of nursing homes, pay the extra costs of disability, and make her goal of academia a reality – 'self-funded freedom'.*

*In 1999, Fiona took up a PhD scholarship in Queensland, graduating in 2004 and working as a university disability studies teacher. Fiona is one of the few people with disabilities in senior management. She is successful and earns a good salary. Fiona is currently the Deputy Head of School (Learning and Teaching Scholarship) at Griffith Law School.*

*Nevertheless, she still experiences inaccessibility at work most days – "Life is good but always on notice."*

*Fiona's journey has been a battle. Her success was really driven by luck, good timing, knowing the right people, having mentors and, most importantly, self-belief and motivation. Life should not be so precarious.*

### The importance of dreaming – Having vision in life

Having self-belief and improved expectations is only one piece of the puzzle. Even more important for the individual living with a disability is the ability and opportunity to 'dream' – to have aspirations about life and what they want to get out of it.

Family and support organisations will be the primary facilitators in setting the expectations for individuals to dream and then helping them to define life goals, aspirations and priorities.

Perth Home Care Service (PHCS) adopts the concept of 'deep listening' to understand the 'dream' of the person living with a disability and to help them identify what they need to lead an interesting and fulfilling life.

> *"Any mechanism for disability support funding needs to ensure that there are resources available to assist a person envisage a good life for her/himself. This is particularly important to people who may have experienced years of passive service recipiency and whose personal horizons of what is possible may have diminished compared to nondisabled people." (In Control, August 2010, p. 12)*

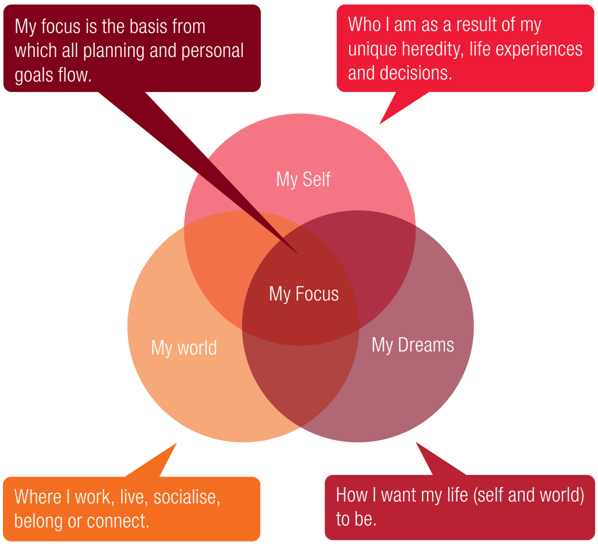
> *"What is it that you want to do with this one, wild, precious thing called your life?"[57]*

In using models such as these, it is important to recognise that life and experience is not static but fluid, and that dreams and aspirations need to be understood in the context of the whole person. Because of this, interpretation and problem solving on the part of the support worker (or family, carer, etc.) is critical to evaluating the dream against the reality; that is, the strengths, weaknesses and underpinning wants and needs of the person with a disability.

Most people have achievable dreams that remain unfulfilled, either because others have shut them down or because they lack self-belief. While we concede this, we must also recognise that for people with a disability, the dream is more often than not a modest one – 'an ordinary life'.

### CPL – facilitating the dreaming process

The Cerebral Palsy League (CPL) has implemented an approach to realise this using 'Service Options conversations' in conjunction with the Personal Outcome Measures System (POMS) framework.[58] The diagram below illustrates the key areas of the framework, while also demonstrating the importance of dreaming for the person living with a disability.



Source: Cerebral Palsy League Brisbane. CPL response to the Productivity Commission Draft Report. April 2011. Appendix 2.

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[57] Mary Oliver; cited in Person-centred practice – Can we really do it? A presentation by Heather Simmons. Living in the West Conference Perth WA. July 2008. [Accessed on 06/07/11].

[58] Cerebral Palsy League Brisbane. CPL response to the Productivity Commission Draft Report. April 2011.

### Personal characteristics/levers

Individuals build their self-belief and level of expectation through *dreaming*, but they are supported on the twin foundations of their personal characteristics and support networks. These are tools that assist the person with a disability to aspire to great things, gain a level of independence and control in their lives, and adapt accordingly when the situation presents itself.

The concept of *resilience* and its role in the lives of people with a disability and their families appears in many personal stories and experiences, particularly in association with themes such as survival, adaptability and personal capacity building. Traditional notions of resilience refer to an ability to realise good or positive outcomes in the face of prolonged challenge, difficulty or stress.[59] Rather than being an individual attribute or stemming from a problem with the individual, resilience should be viewed as an interaction of factors. As such, individuals can adopt strategies to adapt and build resilience. Key to building resilience is recognising and accepting the legitimacy of the challenges one may face.

Most people learn from others in similar situations, allowing them to relate to someone else and see the possibilities as much less abstract and more tangible. Peer mentoring is key to building a person's resilience and strength to pursue their personal vision; however, the challenge will be to help identify appropriate role models in society.

The *ability to problem-solve* is another important mechanism to help a person with a disability build independence, control and the capacity to thrive in modern society. Problem-solving should not be concerned solely with providing the solution, but also with understanding the way to approach challenges, identify and access the right information, and to arm oneself with knowledge and capacity.

This is absolutely fundamental in a new world where the person living with a disability is given choice and decision-making power. How do you support a person with a disability to access and leverage knowledge capital?

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[59] Masten (2001), p. 235; cited in Lemay, R. (2005). Resilience, the Developmental Model and Hope. The Crucial Times. 34, p. 5-6.

## Family and carers

### *The challenge*

Family support can be provided in a nurturing or resentful environment, or usually somewhere in between – caring but struggling. While involuntary family support is sustainable for a period of time, without systemic help most people reach their limit and begin to see their role as a 'chore'. The provision of enduring, involuntary support is a key contributor to the dependency culture and impacts on the whole family, including the person with a disability.

There has undoubtedly been a tendency for support organisations to focus on the individual with a disability, providing rationed services to them and relying on family to make up the (large) unmet need. In conjunction with poor support for families, this situation has contributed to the poor health and wellbeing levels of carers and led to crisis situations that often force parents to abandon their loved one with a disability.

### *Moving forward*

The family is usually the unit of primary support for a person with a disability, and as such will feel a substantial impact from the changes to the way disability care and support is funded and made available.

In a future system, support organisations will be required to focus on the needs of the individual with a disability, building their capabilities and seeking to understand their desires. Their family unit must be included in this process, with the support organisations engaging with both the individual with a disability and their family in partnership.

#### Supporting families

Natural supports play a pivotal role in meeting the needs of people with disabilities. This will continue to be the case, despite improvements in the availability and provision of formal supports. The NDIS serves to complement the bulk of support provided informally, rather than replace this type of care and support.

While the NDIS does not replace the role of natural supports, it certainly has a place in supporting families to cope and continue to provide such vital care and support. This involves ensuring that the disability system as a whole supports families to care for the individual with a disability, as well as ensuring the presence of supports that directly address the carer's own needs.

Key supports needed to sustain this caring role and improve the poor outcomes traditionally associated with the role (such as isolation, anxiety and stress) include respite; emotional support, including counselling; financial assistance; physical assistance; access to health care; and training and education.[60] Research has found that training and support interventions for carers have produced improved outcomes for them. For example, improved psychological health was found in carers who were taught strategies for coping.[61]

Peer supports and informal networks also serve as an important mechanism for supporting families. Other families and individuals sharing similar experiences serve as good and reliable sources of information and support. It will be important to help families identify and link in with these informal peer support systems.

### *Box 4: Ava's story – part 1*[62]

*Ava is a six-year-old girl and while she looks just like any other child her age, she has Dravet syndrome – a epilepsy condition. In order to navigate life, Ava (and her family) have individual needs. These are not always met.*

*"… we have been tested to the cores of our being. Its like living with a time bomb but not knowing what time it has been set to go off. There is a continual knot in your stomach and I can not remember what it's like to relax anymore."*[63]

*Taking care of Ava with limited support and in a hard to navigate environment has been difficult on Ava's parents and siblings, but particularly her mum and primary carer, Joylene. While Joylene intended to return to work after having children, this has not been possible due to the commitment required to care for Ava. Joylene has been out of the paid workforce for almost 10 years.*

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[60] ABS, 2010d; cited in PC. (2011). Disability Care and Support. PC Inquiry Report. No. 54, July 2011.

[61] Selwood, A., Johnston, K., Katona, C., Lyketsos, C. and Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. Journal of Affective Disorders, 101(1–3), p. 75–89.

[62] Donovan. (2010). Our story of life with a child with special needs. Submission to the Productivity Commission. 15 June 2010.

[63] Ibid., p. 3.

### Family expectations

Having expectations is important in striving for and realising one's goals and aspirations. Furthermore, these expectations and self-belief are shaped by the environment and the experiences along the way – hopefully in a positive manner. However, negative or limiting attitudes are very often inherited and internalised. The family, given their enormous involvement in the life of a person with a disability, are not only key in helping form the expectations of their family member with a disability, but also in formulating their expectations for themselves and their family members.

### Support vs. freedom – What is the balance?

Striking a balance between supporting and protecting a family member with a disability and giving them freedom and an opportunity to be independent is important. While acknowledged in theory, families can be reluctant to try new things or permit their child with a disability to take risks. Even in well-functioning families with good intentions guiding their behaviour and decision making, a culture of overprotection can contribute to the limitations placed upon the person with a disability.

Society needs to allow children with a disability to be part of the community, experiencing everyday life and being prepared for key milestones in their life such as moving into employment or out of the family home should they wish to do so. This obligation exists regardless of whether the individual chooses to act on these opportunities or not. To make this happen, families need education to help them recognise and support the normal transition.

Families should be caring but not overwhelming; it is particularly important that family members are not the only people involved in an individual's life.

People with a disability need people around them with a range of perspectives to support them in making the right decisions for themselves at each stage of their lives.

# Specialist support organisations

## *The challenge*

Most disability funding in Australia is currently dispensed through non-government organisations, with much of this provided through block funding. As such, and despite providers' best intentions to put the individual at the centre, the principal customer is currently government. Services are provided within government-prescribed service definitions, thereby inhibiting individuality.

Workforce challenges are one of the sector's main obstacles to change. Poor pay, patchy leadership, inconsistencies in induction and training, and limited initiative and innovation in engaging with and supporting clients are but some of the enduring issues. This is critical because the formal workforce will need to grow significantly to meet the increasing demand.

However, much of the frustration experienced by the sector relates to limitations within the current system. The disability system itself is very likely the primary challenge faced by service providers (or support organisations, as we refer to them in this paper). Support organisations currently have difficulty coping within a system that is failing and this drastically limits their ability to innovate, be flexible and provide choice.

Support organisations, particularly those that are well established, with deep-rooted culture and behaviour, may find it challenging to shift to a new way of thinking and working. In the short term, even after the introduction of an NDIS, users of the system – people with a disability, their families and carers – will be reliant on the familiarity of existing, known support organisations to deliver their services and supports. Without change in their support organisation, these people will be compromised in their ability to benefit from the new system, and will very likely be stuck in the old service model.

However, over time and with support, users will want to begin to build personal capacity, and they will be better able to take full advantage of the choice and empowerment that the NDIS affords them. By this time organisations will also need to have transitioned and be operating within the principles of person-centredness and be flexible enough to meet the needs and wants of people with a disability and to support their participation as citizens in the community.

The implications for organisations that do not embrace this change will be a reduction in market share over time.

## *Moving forward*

At a policy level, the most profound effect on the relationship between support organisations and clients will resemble traditional market analysis – demand and supply.

- On the demand side, support organisations will need to create a range of systems and processes that enable and support people with disability, their families and carers to exercise choice, voice and control as central drivers and enablers of opportunities in their own lives.
- On the supply side, the NDIS is expected to generate a sustainable, diverse, person-centred and responsive disability service system by providing incentives to providers who will be sufficiently robust and capable of operating in a more consumer-/demand-driven environment rather than a program-based welfare/charity model.

This development means that the business of support organisations (most of which are NGOs) in the changed disability sector will be – with the help of family – to support people with disabilities to understand their values and vision and to provide the supports needed to move towards those goals throughout their lives. To achieve this in a new world of disability support, NGOs need to build knowledge capital (ideas, innovations, skills) and social capital (networks with community, government and business). Furthermore, NGOs will need to support this capital development and support system by building material capital (revenue, assets, infrastructure).

Support organisations have the opportunity to redefine their role in the market, but they need to be aware of the risks and complexities associated with the transition. For example, the NDIA will need to consider the potential of 'thin markets' arising – as may be the case in certain geographic localities or specialist fields. In such circumstances there could be reduced real choice or a situation where services cannot be viably provided without underwritten support.

We consider here how support organisations can better support people with a disability and:

- what kind of internal changes support organisations will need to make
- what will be the role of support organisations in meeting the needs of people with a disability, considering the three tiers of support defined by the PC?[64]

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[64] See Section 3 of PC report.

### Deep listening – Understanding and supporting the individual

For the person living with a disability, having values and a vision in life is of the utmost importance. It is even more critical in a world of individualised funding packages and person-centred support. While the individual is central to this concept, the journey can often only be taken with the help of a facilitator or partner; in this case, the support organisation.

Models of deep listening such as those used by PHCS and CPL centre on understanding the needs, goals and preferences of their clients – people with a disability and their families – gauging what success looks like for their clients, and identifying and accessing available services and supports to help realise these goals and aspirations. Underpinning this approach are three themes:[65]

- Outcomes first – What outcomes does the individual (and their family) seek in all aspects of their life and what choices are available to them
- Person-centred supports as a means, not an end – The supports/services an organisation provides are not the end in themselves, they are simply a method of assisting people to achieve their personal outcomes
- Person-directed planning – Rather than planning being developed around the person, planning is directed by the person, where necessary with support and facilitation.

Some examples of the Local Area Coordinator (LAC) model in Western Australia work in harmony with this concept of deep listening, as the LACs currently perform an interface role and are therefore well placed to understand an individual's needs, identify local services and supports that are available, and link the two together.

> *The NDIS shifts control of the funding process to people with a disability and their families – a transfer of purchasing power.*

### Transitioning to a truly personalised approach

Many organisations carry with them the legacy of outdated service models, and have economies of scale and scope which may benefit or hamper them in effectively developing personalised responses. While a number of providers have made considerable progress already, that development is often uneven and subject to particular local circumstance. Existing program-based funding often militates against innovation by service providers if they seek to prepare for the major challenges posed by transition to a person-centred funding model.

An effective transition to the proposed market architecture for disability services must take account of the evolving client/consumer journey, and should ultimately be deemed successful only if it enables people with a disability to achieve citizenhood.

The focus of industry development and transition planning therefore needs to be on the effective interaction between the supply and demand features, the fundamental purpose of which is to provide choice for individuals and access for all assessed as needing support. This also requires governments and the sector to work in partnership.

Whether support organisations are providing specialist disability services to Tier 3 clients receiving individual funding, or mainstream and community activity at the Tier 2 level, they will need to adopt a true personalised approach when interacting with people with a disability and their families.

### How can support organisations better understand and support people with a disability?

As most disability service providers recognise, understanding and supporting people with a disability requires:

- establishing positive and respectful relationships with the individual and their family (and circle of support). Collaboration is important
- asking the right questions to uncover the essence of what will make a meaningful difference in individuals' and their families' lives. For example, earlier we referred to models at the support organisation level that drive conversations and assist in uncovering the aspirations and dreams of individuals
- focusing on outcomes using a quality of life framework. The eight quality of life domains presented earlier pinpoint what is needed at a broad level for people with a disability to lead enriched lives, despite their level of impairment, function or capacity

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[65] Cerebral Palsy League Brisbane. CPL response to the Productivity Commission Draft Report. April 2011. Appendix 2.

- building creative solutions without being constrained by service definitions
- informing and empowering the individual. Access to good quality information will help individuals with a disability and their families to understand what is available and possible, weigh up options and assess risk, develop capacity, and make choices more confidently in their lives.

### Workforce capability – What does it take to support a person with a disability?

Without a committed and capable workforce, organisations will be unable to support the needs of people with a disability living in our society. So, what needs to change? The sector needs to:

- recruit and develop support workers that have a dedication to and mindset of 'doing what it takes' when it comes to working with people with a disability and their families
- instil a culture of innovation in the identification and delivery of strategies to engage with and support people with a disability and their families – it is about thinking 'outside the box'
- bridge the gap between Tier 3 individual support and Tier 2 community support, creatively building support without always needing specialist workers
- establish a system of leadership to promote the desired culture and monitor its application. This will involve supervision and monitoring frameworks, as well as establishing practice leaders who will invest time, commitment and passion in driving and nurturing such a change.

Executive and non-executive leadership in disability sector organisations will need to develop comprehensive plans and planning systems for creating individualised responses that will support the change to re-orient organisations in readiness for the NDIS.

### The interaction of various organisations in the sector

As part of the NDIS, the PC report proposes the establishment of a new concept in sector development – disability support organisations (DSOs). In the new market of consumer choice, DSOs will include both new and established organisations dedicated to the provision of intermediary services including personal planning, assembly of support packages, administrative and management services, advocacy services, mentoring and capacity building, and brokerage services.

DSOs will be key to achieving a truly person-centred approach to planning. Much of current practice in this area is said to operate in this manner; however, in actual fact it is the provision of limited options within the existing pool of services that are available. There is often little ingenuity in planning and coordination.

DSOs will need to provide support and assistance along a continuum – whether it be full coordination and management responsibilities or guidance and administrative support to facilitate the adoption of self-directed funding and choice. DSOs will require adequate skills and experience to be able to fulfil such roles in a flexible and responsive manner.

As we will see later, DSOs will also have a critical role in building community capacity, championing accessible mainstream services, and in achieving true citizenhood for people with a disability. Along with systemic advocacy groups, DSOs will:

- ensure flexibility and responsiveness
- minimise and manage excessive bureaucracy
- create and sustain effective community resources
- engage the community
- stay close to people and tell the truth.[66]

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[66] Uditsky, B. The role of advocacy in an environment of individualized funding: some ideas on safeguarding individualized funding into the future. Presentation by CEO, Alberta Association of Community Living. Undated.

## Mainstream services and supports

Mainstream agencies are in the business of providing universal services and support that respond to the needs of all Australians. These agencies include health, education, community services, justice, transport, employment and housing.

In this section we consider several mainstream systems, the challenges they currently face and potential solutions.

### *The challenge*

Mainstream services and support agencies have a responsibility to ensure equitable and universal access to their services. Nevertheless, there are current obstacles for people with a disability in accessing these mainstream universal services and supports.

The system is fragmented. While there are pockets of accessible infrastructure, there is misalignment between resources and the way the system is organised. For example, within transport there is a limited level of capacity; however, there is no flexibility embedded to enable the use of this capacity.

Currently it is highly likely an individual with a disability will be 'stuck', or face unnecessary obstacles, simply because the various components of the transport domain do not speak to one another.

> *"… my most significant on-going expense is the cost of transport to and from work. I am totally reliant on using taxis… The high cost of transport is an active disincentive in obtaining and maintaining employment …" (PC report, p. 4.22).*

The barriers associated with transport are symptomatic of the way in which disability supports in general are constructed and delivered. The integration between specialist disability services and mainstream services is currently flawed.

## *Box 5: Matthew and Ronni's story* [71]

*Matthew is almost 10 years old. He has severe and multiple disabilities and chronic complex health needs. Matthew spent much of his first few years interacting with the health system through frequent hospitalisations and surgeries.*

*He has since transitioned into the disability system and with his family has experienced numerous roadblocks in meeting his needs. Soon after his sixth birthday, Matthew received his firstwheelchair – this was six months delayed.*

*Matthew does not receive enough support at school and for a while, Matthew's family self-funded therapy to help him. This was financially unsustainable.*

*For Matthew's family, thinking about the future is both scary and depressing.*

*"We know that we cannot continue to provide all his daily care… Sadly we also know from current waiting lists that unless things change this will mean we must abandon Matthew in the future."* [72]

> *"… the current (education) system has little capacity to meet the needs of students with disabilities and a lack of resources to ensure their full participation in classrooms and schools."*
>
> *This may "drive parents into choosing specialist settings despite their desire for their child to attend local schools."* [67]

We know that unemployment, under-employment and stressful working conditions have adverse impacts on a person's health.[68] Nevertheless, approximately 800,000 people with disabilities in Australia are in receipt of the DSP as their primary source of income.[69]

Compared with other OECD countries, Australia has one of the lowest employment participation rates for people with a disability. In fact, across a continuum of employment performance for 29 OECD countries (where 1=best and 29=worst), Australia was ranked 21st, with an employment rate of 39.8% for people with a disability compared to 79.4% for people without a disability.[70]

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[67] National People with Disabilities and Carer Council. (2009). National Disability Consultation Shut Out Report: The Experience of People with Disabilities and their Families in Australia, p. 47-48.

[68] WHO. (2008). Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health. Final Report of the Commission on Social Determinants of Health, Geneva.

[69] PC. (2011). Disability Care and Support. Productivity Commission Inquiry Report. No. 54, 31 July 2011.

[70] OECD. (2010). Sickness, Disability and Work: Breaking the Barriers - A Synthesis of Findings across OECD Countries; cited in Appendix K The disability support pension. Productivity Commission Inquiry Report. No. 54, 31 July 2011.

[71] Wood, R. (2010). Productivity Commission Submission. By Ronni Wood on behalf of my son Matthew. 23 June 2010.

[72] Ibid., p 5.

## *Moving forward*

Whole-of-government engagement is required to develop robust and shared systems for population planning, program design, service delivery and monitoring that promote seamless, person-centred care and support.

In the context of an NDIS, which will cater to a proportion of Australians with a disability, mainstream services and the community will play a key role in:

- supporting those individuals who fall below the eligibility threshold
- preventing escalations in care needs
- reducing the number of crises.

To protect the integrity of funding and maximise the benefits of an NDIS, core government services will need to:

- be held accountable, with assurance that obligations for such activity and support are not withdrawn simply because of the creation of a well-funded entitlement system for individual disability care and support. For example, many mainstream agencies have Disability Action Plans, which more often than not are left dormant. These plans should be reviewed and reinvigorated
- build capacity and capability to appropriately understand and support people with disability; for example, through interagency collaboration, formal training and qualifications, and increased exposure to and interaction with people with a disability
- identify ways to better integrate mainstream and specialist services and supports, such as by having:
    - lead professionals who take responsibility for holding other agencies to account
    - models of care that support the co-location of specialist services with mainstream agencies or multidisciplinary teams.

The NDIS could serve as a catalyst to improve the way in which mainstream services and supports are established and operated – the question is how.

### Transport

Access to reliable and affordable transport is a fundamental piece of the puzzle when it comes to promoting independence and facilitating participation in such activities as education, employment, leisure and health care.[73] The transport system needs to change so that existing infrastructure investment is linked up and can be utilised by people with a disability in the most efficient and effective manner.

Greater human interface to support the community as a whole and reduce the disadvantage of people with a disability may be one way to mitigate the transport-related access challenges. Greater investment in human capital and encouragement of more creativity from the people within and running the system is necessary to facilitate accessibility and inclusion.

Assistive technologies could also be better utilised to make a difference; for example, the use of geospatial telecommunications technology to assist individuals with cognitive or other disabilities to adapt to changes in circumstance. As an innovative way to address transport challenges posed by language barriers, the Japanese subway system works on a topological layout with colour coding for different lines.[74] In this system, each train line has a different colour and letter and each station is consecutively number-coded.

The implementation of an NDIS cannot remove the current barriers that exist in the transport system. It is by no means a solution in itself. However, by investing in community capacity building measures and shifting societal attitudes to the value that people with a disability contribute to our society, the NDIS may be able to work towards promoting social inclusion as a mechanism for overcoming these transport barriers.

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[73] Australian Government. (2009). Shut Out: The experience of people with disability and their families in Australia. National Disability Strategy Consultation Report. Prepared by the National People with Disabilities and Carer Council.

[74] Understanding Japan: Navigating the Tokyo Metro. http://www.jrpass.com/blogs/navigating-the-tokyo-metro

## Education

There is a large disparity in educational outcomes between Australians with a disability and those without. In 2009, 25% of people with a profound or severe disability aged 15 to 64 completed Year 12.[75] In comparison, 55% of people without disabilities completed Year 12. This disparity continues across the education pathway for people with a disability, with approximately:

- 13% of people with a disability aged 15 to 64 completing a bachelor degree or higher, compared with 20% of people without disabilities[76]
- 58% of 25 to 44 year-olds with a profound/severe core activity limitation having no post-school qualification, compared with 28% of people in the same age cohort without disabilities.[77]

The National Disability Strategy highlights education as a key pillar in moving towards a more inclusive and productive Australia. Higher levels of educational attainment are linked to better employment, financial and health outcomes.

Acknowledging the important links between education and other key indicators, the COAG made commitments to:

- improve Year 12 or equivalent attainment up to 90% by 2015[78]
- double the number of higher education completions by 2020.[79]

As part of these goals, it will be important for state and territory governments to focus on the supports and changes needed to ensure that improvement occurs for people with a disability. This is particularly relevant given that just under 90% of students with a disability attend mainstream schools.[80]

### *Box 6: Ava's story – part 2*[81]

*Ava is one of five children in her class at Glenallen – a special needs school. She spends four days at this school and one day at the local Catholic school through a dual learning program. Ava's mum, Joylene, has noticed the positive outcomes Ava has achieved by attending Glenallen. Joylene believes that the mainstream environment would not be able to achieve this progress.*

*However, the road to getting Ava enrolled at Glenallen was littered with obstacles. While Ava has episodes of epilepsy, language delays and behavioural issues (requiring regular assistance from a therapist) that are similar to autism, her IQ is low average. As such, she did not meet the criteria for special needs schooling.*

*Through self-initiated research, Joylene came across Glenallen, a special needs school based on children's disability and high medical needs and with no IQ criteria, which made all the difference. The alternative would have been "… the mindfield of mainstream with inadequate funding for a full time assistant for her and teachers having to deal with a child they are not trained to deal with."*[82]

*Nevertheless, Ava's hidden disability can still make her feel like she does not fit in anywhere. For example, one of the parents from Glenallen, where most students have a physical disability, commented that there did not appear to be too much wrong with Ava. Conversely, she is quite different in her behaviour and learning ability compared with other mainstream school students. She is a minority within a minority.*

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[75] ABS. (2011). Disability Australia 2009. Cat. no. 4446.0.
[76] Ibid.
[77] ABS. (2011). Disability, vocation and education training, Australia, 2009. Cat. no. 4438.0.
[78] COAG.(2009). National Partnership Agreement on Youth Attainment and Transitions.
[79] COAG Reform Council. (2010). National Agreement for Skills and Workforce Development: Performance Report for 2009.
[80] Students with disabilities working group. (2010). Strategies to support the education of students with disabilities in Australian schools. Report to the Minister for School Education. 15 December 2010.
[81] Donovan. (2010). Our story of life with a child with special needs. Submission to the Productivity Commission. 15 June 2010.
[82] Ibid., p. 4.

State and territory government funding has increased the proportion of students with disabilities in mainstream schools and promoted an inclusive education for all in the last 10 years. This shift is consistent with the well-documented benefits of genuinely inclusive education models. For example:

- Better academic performance in inclusive education settings rather than special schools[83], with those in segregated education losing percentile rankings in comparison with their peers in regular classrooms[84]
- Greater opportunity to become part of their local community. Students with disabilities educated in neighbourhood schools are more likely to participate in weekend activities with people they see every day at school. These interactions are less likely if students attend a special class or school some distance away[85]
- Opportunities for development of appropriate attitudes towards people with a disability. Changing attitudes requires both presenting information about disabilities and also engaging with people with disabilities.[86]

A submission to the PC in relation to the education sustem's responsibililty to students with a disability and the relationship that is required with the NDIS states:

> ***"Education and training systems must be held responsible for delivering good education outcomes for all, including those with disability. The relationship between the NDIA and education systems needs to be collaborative and always focused on supporting good education and training outcomes." (NDS, April 2011, p. 10)***

However, merely being present does not equate to true inclusion and equality in learning opportunity, and many parents would prefer to opt for specialist schools because of the shortcomings of the mainstream system. The focus should be on choice and optimising learning and educational outcomes.

It is a key responsibility of jurisdictions to provide accessible and inclusive education to all individuals. In addition to this basic requirement, the NDIS will better support individuals with a disability to access a good education by providing necessary goods and services that assist an individual every day.

Achievement of good education outcomes across their lifespan for people with a disability needs to be front of mind in determining the most appropriate policy. Framing decisions around the principles of exercising rights and choice and removing obstacles to inclusion and citizenhood are sensible starting points.

### Employment

Being employed in a fulfilling job has psychological benefits that flow on to physical, social and economic benefits. In the UK, Dame Carol Black's 2008 review[87] of the health of Britain's working-age population was the vehicle for acknowledging the key links between work and health and getting both employers and government involved. Not only does work improve health outcomes, it promotes participation in society, independence and financial stability, all of which are protective against mental health problems.

For people on disability benefits, there is strong evidence to suggest that re-employment leads to improved self-esteem, improved physical and mental health, and reduced psychological distress.[88]

Without serious policy reform, for many Australians with a disability the prospect of meaningful work will remain a distant and unlikely scenario, with many consigned to the prospect of a life of welfare.

In moving forward, there needs to be a focus on both open and supported employment. Improving mainstream employment involves engaging with the business community.

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[83] Peetsma, T., et al. (2001). Inclusion in Education: comparing pupils' development in special and regular education. Educational Review, 53(2), p. 126-135.

[84] Calberg, C., and Kavale, K. (1980). The Efficacy of Special Versus Regular Class Placement for Exceptional Children: A Meta-Analysis. Journal of Special Education 14, p. 295–309.

[85] Wills, D., and Jackson, R. (2000). Report Card on Inclusive Education in Australia. Interaction, 14(2&3), p. 5-12.

[86] Westwood, P., & Graham, L. (2000). How many children with special needs in regular classes? Official predictions vs teachers' perceptions in South Australia and New South Wales. Australian Journal of Learning Disabilities, 5(3), p. 24-35.

[87] Black, C. (2008). Working for a healthier tomorrow. Dame Carol Black's Review of the health of Britain's working age population. Department of Work and Pensions.

[88] Waddell, G. and Burton, A. Kim. (2006). Is Work Good for Your Health and Well-Being? Report commissioned by the UK Department for Work and Pensions.

## *Box 7: Peter's story*

*Peter is the 2011 WA Young Person of the Year. He became quadriplegic at 16, after an accident for which there was no compensation. He battled to get access to tertiary education; though he was academically eligible he found difficulties in getting the necessary personal care. Eventually he succeeded in getting the bare minimum of care hours and was awarded his degree in psychology.*

*He has been working as a youth development officer for about five years and has now taken on extra hours as a youth counsellor. However, despite being cited as an inspiration by his employer and winning numerous work and community awards, his employment has been in constant jeopardy because of inadequate hands-on assistance to help him with the manual tasks that he can't manage.*

*Peter is currently working 50 hours a week and estimates he needs around 40 hours of assistance. While he develops and delivers the youth program, he needs someone else to fetch printing, open doors, set up events and help him with transport. He is only eligible for 10 hours of physical assistance, which makes his job almost impossible. Ironically, if he resigned he would be eligible under a state-based scheme for 40 hours of assistance, but only as long as it was used for leisure activities and not work.*

*At one stage, Peter resorted to making huge personal sacrifices, using his much needed home care assistance allowance (for being fed, bathed, toileted and assisted in and out of bed) at work, which meant that it was his family who did all of that.*

*Peter has lobbied for a number of years, stating that he wants to get off the DSP and that if he gets the right assistance, not only will he be paying tax but so will his carer. Despite intense lobbying, nothing has changed.*

> ***"... employment outcomes require an appropriate mix of supports, community and business receptiveness to the involvement of people with disabilities, good economic incentives to work, and expectations of social and economic participation. The current system has not sufficiently promoted these features."***[89]

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[89] PC. (2011). Disability Care and Support. Productivity Commission Inquiry Report. No. 54, 31 July 2011. p. 115.

### Decreasing employer apprehension in hiring people with a disability

There is a clear rationale in employers contributing to the realisation of good employment outcomes for people with disabilities – they will be the agents of change and as such will need to be educated and actively engaged to adequately fill this role.

Employers will need to work with governments to assist people with disabilities to enter or re-enter employment by:

- improving accessibility to their work environment
- sponsoring and partnering with government to deliver targeted employment, training and transition programs
- harnessing social capital through business relationships and community networks to link individuals to meaningful employment opportunities.

In moving towards change, corporations could adopt an audit-of-readiness approach for accessibility. The audit framework could include a preparedness to better case manage potential employees living with a disability and make other physical and cultural changes required.

> *Some evidence suggests that businesses able to handle diversity and disability are better positioned to succeed in a globalising economy as they are equipped to interact with a more complex customer base, environments and cultures.*[90]

Other strategies necessary to create the landscape for change include:

- changing business practices and employer attitudes
- wage subsidies for employers and job brokers
- incentives and support for employers
- innovative job creation.

In order to further incentivise and drive these changes, the NDIA could adopt a transparent rating system to report on outcomes for larger-sized employment providers. An outcome-based performance framework such as this would require periodic evaluation for validity. This proposal differs from the current arrangements, where providers are generally rewarded for throughput.

### Government as an exemplar

There is an opportunity for government workplaces to lead the way, setting an example for private sector employers to operate as change agents. This will be important in demonstrating to business that there is not only a responsibility on workplaces to actively facilitate employment for people with a disability, but that it is feasible and already taking place.

For example, in line with the Ready, Willing and Able initiative in NSW, mainstream government departments can play a role in increasing employment opportunities for people with a disability through:

- directly employing people with a disability (through Disability Employment Services) and having a minimum target per year
- procuring goods and services from Australian Disability Enterprises (ADEs).

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[90] Symonds, A. (2008). Business urged to take on disabled staff. Australian Financial Review, 28th July 2008.

### Housing

A key lifestyle domain for all people is that of housing – a safe, stable and secure home. In the case of people living with a disability, achieving this can often be fraught with difficulty.

One of the key challenges facing a subset of the disability population is access to supported accommodation. The NDIS, as described in the PC report, would have a key role in funding this specialist housing, incorporating innovative approaches, given the current shortages. In addition, home modifications to public and private housing (to better facilitate independent living arrangements) would fall within the remit of the NDIS (as part of the broader assessment of need process).

However given the narrow scope of responsibility for the NDIS, it will be important to ensure that mainstream housing, particularly public housing, continues to be invested in to ensure people with a disability have access to affordable and stable accommodation.

The design of a dwelling as well as its location in relation to public transport and other infrastructure are key factors (and often barriers) for people living with a disability and therefore limit the pool of available housing stock.

There is opportunity to increase the availability of appropriate and affordable housing stock for people with a disability by building partnerships with developers and harnessing private capital. For example, the National Rental Affordability Scheme is a key vehicle to attract investment in building new affordable rental properties. Other policy levers to improve the sector's capacity to offer better access to housing and accommodation include capturing the full amount of Commonwealth Rental Assistance.

> *"Problems regarding the availability and location of dwellings are common to all prospective clients of public housing. For that reason, decisions about where to locate public housing and how much to invest should remain a mainstream policy concern."*[91]

The key theme here is the importance of the various agencies working in partnership to ensure that mainstream services are accessible to people with a disability and that specialist supports provide an appropriate complement to existing broader supports.

By collaborating, jurisdictions will be able to identify better and more efficient ways of working together, particularly through regulation and pooling of resources and funds.

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[91] PC, 2011, op.cit., p. 242.

## NDIA: Funder-regulator-facilitator

Government is currently the funder and purchaser of services, prescribing the types of services and supports an individual should receive. The shift in choice, decision-making power and funds/transfer payment to the person with a disability means that government's role will need to change.

### *Moving forward*

As well as funder, government's new role, through the NDIA, will be as regulator-facilitator, but not purchaser or prescriber. The NDIA, as an independent statutory body, will have a critical role in facilitating the systemic change that is needed in the support organisation system, in mainstream services and across the community to ensure that the necessary supports are in place to facilitate the transfer of control and to optimise individual and family capacity.

### Regulator–facilitator roles and responsibilities

An overview of key roles and considerations of the regulator–facilitator are listed below. The PC report describes these functions, which align to three broad areas: the relationship with people with a disability, their families, and the community; arrangements with support organisations; and broader system functions.[92]

**The relationship with people with a disability, their families and the community**

- Assessing needs, facilitating planning, and determining the support package needed by the individual
- Provision of accessible and supported information to people with a disability, their families and the community
- Increasing awareness and facilitating culture change
- Building capacity in the community and cultivating reciprocity
- Facilitating linkages with community groups and other government services.

**Arrangements with support organisations**

- Overseeing regulation of support organisations to better inform consumers
- Promoting and incentivising capacity building initiatives targeted at individuals and families
- Building system capacity in delivering person-centred approaches, including assisted decision-making
- Promoting innovation and best practice in the sector.

**Broader system functions**

- Governance structures that facilitate the efficient and accountable achievement of NDIS objectives
- Broad prescription of outcome indicators and benchmarking
- Monitoring and enforcing quality through the collection, analysis and reporting of a whole range of data
- Research, development and innovation.

### Lessons from other jurisdictions and key considerations

In exercising these responsibilities it will be critical for the NDIA to institute a support system and governance framework which focuses on achieving the intended outcomes.

Alberta, Canada[93] has a long history rolling out its individualised funding program. It has done so in spite of problems arising from the absence of parallel investment in capability building. Individuals were given the facility of a personal budget and transactional control. However, in implementing the change, there was little assistance provided to individuals and their families. The combination of factors resulted in no actual change to the services and supports being purchased – ie no real control or choice. The funding model in itself was not flawed; however, the lack of capacity building across the main stakeholder group meant that the implementation was not as successful as it could have been.

Similarly, the NDIA needs to be careful to avoid 'templating', where individualised funding models are pursued in order to achieve unrealistic targets of personal budget uptake. In these instances there is a real risk to the integrity of the personal control model. In considering the move to choice and personal control, there need to be appropriate controls in place to mitigate the potential for perverse incentives that promote the rolling out of mass 'imitation' individualised packages (that is, packages under the guise of personal control, but in fact just a set of service options) for the sake of reaching a set uptake target.

The UK Government set a target for authorities to provide a personal budget to 30% of adults eligible for social care. The Association of Directors of Adult Social Services (ADASS) survey[94] found that approximately 35% of eligible people were on a personal budget as at March 2011. The survey, however, indicates that most of the arrangements were council-managed personal budgets – ie 67% of people were on managed budgets, while 26% were on direct payments.[95]

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[92] Table 9.1 of the PC report, p. 406.

[93] Uditsky, B. The Erosion of Individualized Funding Alberta Association for Community Living. Undated.

[94] ADASS. (2011). Putting People First: 3rd Year Progress. Presentation by Jeff Jerome. April 2011, updated 29 June 2011.

[95] Ibid

## *Box 8: Nick's story – part 2*

*Nick and his girlfriend Sarah are uniquely special to each other. Nick is tall, Sarah is very short; Nick can't speak, Sarah is verbally able; Nick is 26; Sarah is 37. Both have a similar level of intellectual disability. Although generally very protective of his own personal space, Nick loves kissing and cuddling with Sarah and even likes her blowing wet raspberries on his face or tugging at his nose. For them these are expressions of their physical intimacy. They are supported on their 'dates' together, enjoying at movies, concerts, meals out and spending time at each other's houses. Nick has an extraordinary visual memory. For weeks after Sarah has visited he points out where she sat, walked and movies they watched. Recalling these details taxes the memories of family and staff, but for Nick they remain vivid and important to share. They are happy memories that fill his home, and provide him with months of ongoing pleasure.*

*So, what does Nick want? He wants to be happy, healthy and safe. He wants to love and be loved, and to be listened to and understood. He wants friends and opportunities to share fun and experiences with them. He wants to belong and be valued. He wants to spend his days in activities that are meaningful and enjoyable for him and to feel encouraged, excited, stimulated and challenged by those experiences. He wants to feel pride and satisfaction in his achievements. He wants the chance to contribute to the lives of others. And he wants to have something to look forward to just around the next corner in his life journey.*

# Citizenhood and community

## *The challenge*

Public awareness of the extent of severe disability in Australia is low, with the extent of disability massively hidden. While much of this lack of knowledge is inadvertent, some people prefer ignorance, as it can be uncomfortable to deal with the reality. More than half of the submissions received for the Shut Out report dealt with the experience of exclusion and the impact of societal views.[96] Respondents raised the need for greater focus on public awareness campaigns about disability.

Many people would argue that individuals with a disability are indeed included by way of living in the community. However, it is not enough for a person with a disability to reside in the community and undertake activities in a community setting; this does not equal social inclusion or community participation – it is simply community presence.[97]

What can aid mainstream culture to grow more comfortable with and available to people with a disability? What part can the NDIS play?

## *Moving forward*

Society plays a fundamental role in facilitating the shift to a more equitable disability care and support system and inclusive society. Community inclusion defines this shift and involves:

- increasing awareness of disability
- educating society about disability
- changing community perceptions towards people with a disability so they are seen as members of the community and engaged with as such.

> *"There are things money just can't buy – friends, belonging, being seen as a contributing societal member, being needed by others, love."*[98]

### Awareness and culture change

To make a real difference, awareness raising and culture change require a shift from traditional public awareness campaigns to more meaningful and influential avenues that involve human contact. The NDIS provides a potential vehicle to facilitate increased awareness and trigger a ripple effect in mainstream culture. This involves partnerships at all levels – government, community, non-government organisations, business and the NDIA.

Shifting the way society not only thinks about people living with a disability, but the way it accepts and embraces this diverse group of people is a goal to be pursued.

The vision is for people with a disability to be part of the community and contribute to community life through:

- reciprocal relationships with other people from all walks of life
- a feeling of safety and belonging in their surroundings
- expectations from the community that the individual will contribute to and enrich their lives
- strong networks and relationships
- a sense of self-worth and value on the part of the individual with a disability.[99]

Community development and education has a key role in promoting social inclusion. There are many examples of programs and initiatives which do this, including:

- Bar None – A project of the Victorian Office of Disability that involved training community newspaper journalists in how to portray people with a disability while supplying relevant stories from people with a disability noted for doing particular things in their local communities
- Count Us In – A Western Australian broad community education and information campaign
- 'Talk' Disability Rights Commission UK and others – In the UK from 2006 the Disability Rights Commission produced a series of advertisements turning the experience of people with a disability in employment on its head. The newer Equal Opportunity and Human Rights Commission in the UK has followed up with a series on their website called Equally Different, where a range of well known and ordinary people from different backgrounds (culturally and linguistically diverse, disabled, war veteran) tell why they are different.[100]

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[96] Australian Government. (2009). Shut Out: The experience of people with disability and their families in Australia. National Disability Strategy Consultation Report. Prepared by the National People with Disabilities and Carer Council.

[97] Bigby, C. & Clement, T. (2010). Social inclusion of people with more severe intellectual disability relocated to the community between 1999-2009: Problems of dedifferentiated policy? La Trobe University.

[98] Uditsky, B. The role of advocacy in an environment of individualized funding: some ideas on safeguarding individualized funding into the future. Presentation by CEO, Alberta Association for Community Living. Undated.

[99] Hoedt (2002); cited in Jenkins, S. (2010). Submission to Productivity Commission on a Long Term Disability Care and Support Scheme.

[100] Jenkins, S. (2010). Submission to Productivity Commission on a Long Term Disability Care and Support Scheme.

### Promoting social connectedness

The development of fellowship and connection is a critical element in achieving an inclusive Australian society where people with a disability are treated as valued and contributing citizens.

We are social creatures, all of us, and our lives are enriched by the varied and interesting relationships and networks that we develop over time – through schooling, employment, travel and all the other experiences we have across our lifetimes. People with a disability, however, are often excluded from participating in these ordinary experiences through a lack of integration within community life and a tendency to be 'dealt with' in the disability arena, via separate supports and activities, hidden.

It is impossible to develop robust and fulfilling relationships when one is not afforded the opportunity to be among peers and others within society. The implementation of an NDIS will not on its own build social networks for people living with a disability. What then needs to happen for this interconnectedness to flourish and touch the lives of people living with a disability?

The role of DSOs in supporting individuals with a disability was raised earlier in the paper. Here we consider DSOs in their broader role of building community capacity and promoting social connectedness. The PC report refers to two key avenues for engaging community: community capacity building and not-for-profit organisations.[101]

DSOs can be viewed as the intersection of these two 'routes' and as such will need to be actively involved in driving the following activities:

- increasing awareness about disability and some of the key issues
- advising mainstream businesses, community groups and other non-government organisations on becoming more accessible
- linking individuals with organisations or groups and opportunities that align with their interests
- helping people with a disability to establish intentional networks and relationships – 'circles of support'.

The establishment of intentional networks is a key avenue to promote social connectedness. These types of programs and interventions have helped to build reciprocal relationships and friendships for people with a disability. In British Columbia, Canada, small groups of family and friends formed a not-for-profit community board established to assist their loved ones with a disability to realise their dreams and goals in a supportive and empowering manner. The established model is run by Vela Microboards Association BC.[102] This model has been successfully trialled in Western Australia by Vela Microboards Australia (VMA) under the auspices of PHCS.[103]

Through harnessing social capital, communities will be able to serve as units of inclusion at the ground level. Individual connections and networks are powerful assets that can be used to help people with a disability to develop relationships with others, as well as creating opportunities for greater participation.

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[101] PC. (2011). Disability Care and Support. Productivity Commission Inquiry Report. No. 54, July 2011.
[102] http://www.microboard.org/what_is_vela.htm
[103] http://www.microboard.org.au/page/how_vma_began

# What needs to be done?

*In this chapter we consider the practical steps necessary to give real meaning to the promise of a fair deal for Australians living with a disability. There is a particular focus on the role of the NDIS in establishing the rights of Australians with a disability. We make four overarching recommendations, seeking to build the capacity of the key experiential components of life and facilitate the much needed transformation in disability care and support.*

The underpinning debate has been framed as a conversation about fairness, yet the public reality is that disability policy and politics has been an argument about services. The argument is almost always at its core about rationing rather than rights or needs. The debate is about:

- the availability of specialist services (or lack thereof)
- access to mainstream services (or their inaccessibility).

Broader access to the economy and culture has been at best haphazard or at worst a near complete 'shut-out' for many Australians living with a disability.

## The cornerstone assumptions of this paper

Four key systemic principles – **fairness** by way of equal rights; **facilitation** and **choice** in exercising rights; and **inclusion** through removal of obstacles to access and participation – have underlined the policy intention of governments and organisations that represent Australians living with a disability.

We contend that these principles should continue to underpin policy going forward. The principles also serve as the cornerstone assumptions of this paper.

### Fairness

- The NDIS concept is a product of the rights-based discourse that has dominated Australian policy thinking on disability for over two decades.
- Only by putting in place an appropriate funding and governance model can that rights-based agenda be satisfied.

### Facilitation and choice

- Establishment of an NDIS is consistent with the PC's final report and is the solution to many of the problems experienced by Australians both as individuals living with a disability and in the community as a whole.

### Inclusion

- Improvements and initiatives that build the capacity of individuals, families, service providers and mainstream culture are essential if the NDIS is to succeed.

## Reflecting on the vision and need

The earlier chapters in this paper developed an outcome-based vision for realising the guiding principles and discussed the change implications for the major participants implicit in this vision, particularly in terms of the capacity of:

- **individuals** to gain the most for themselves out of a person-centred system
- **families** to deal with new opportunities and risks – emotionally, socially and materially
- **support organisations** to innovate and be flexible, not only providing quality and choice for their clients but continuing to be ethical and responsible employers
- **disability workers** to provide support in an efficient way when there is potentially much more individual market–based decision–making by their clients
- public and private **training facilities** to train a massively increased disability support workforce over the next few years
- **government and business** to build infrastructure and provide opportunity for real participation by people with a disability
- **Australia as a whole** to develop and implement strong policy, for universal government agencies to be accountable, and for culture change to filter through society.

All of these are important in order to move forward and achieve a fair go for all Australians, and economic safety and security for Australia.

### *NDIS: An essential vehicle for change*

The NDIS will not provide all the rights and entitlements required for people with a disability to achieve parity. Rather, an NDIS is the most obvious and achievable way of:

- providing an entitlement rather than welfare-based access for 410,000 Australians to the support they need
- changing the cultural and material environment apparent in society at large
- explicitly 'changing the game' when it comes to mainstream and specialist disability services. An NDIS will facilitate mainstream services and culture to interact with people living with a disability in a way that better reflects the rights-based policy stance to which successive federal and most state governments have aspired.

In spite of having a policy based on best practice international rights and standards, Australia's overall performance in outcome and cultural terms has been poor when it comes to Australians living with a disability, their families and carers (whether professional or informal).

So while the NDIS is not of itself the solution to the discrimination and deprivation experienced by Australians living with a disability, it is the recommended precondition for the full gamut of changes needed for Australians to have lives open to the same opportunities and choices available to the rest of society. The NDIS will deliver the environment that Australians living with a disability require to get on with improving their lives and that the community needs to deliver on the largely unfulfilled policy promise of fairness and basic human rights.

## A call to action: Bringing the guiding principles to life

In this chapter, we focus on the potential role of the NDIS and the broader capacity required to effect real change. We put forward four overarching recommendations for bringing to life the guiding principles of fairness, choice, facilitation and inclusion.

### *FAIRNESS – The first principle of social inclusion*

As presented throughout this paper, Australian governments have a long history of supporting the principles of rights and inclusion of people with a disability:

- We actively embraced IYDP 1981 – the International Year of Disabled People
- We followed this with a decade of policy reform, culminating in:
    - the *Home and Community Care Act 1985*
    - the *Disability Services Act 1986*
    - parallel state and territory legislation
    - the first Commonwealth State Territory Disability Agreement 1991
- Through the COAG process, various commitments have been made to social inclusion through improving access to transport, housing and education
- The 2007 Senate report into the funding and operation of the CSTDA recommended the development of a National Disability Strategy
- More recently we have celebrated the 2009 Shut Out consultation report of the National Disability Strategy, and in 2008 we ratified the UN CRPD
- The Senate Inquiry report Disability and Ageing: lifelong planning for a better future was published in July 2011.

However, over this long period little has fundamentally changed towards achieving social inclusion for people with a disability, who are still a very long way from equal rights, fairness and true citizenhood.

Now we have the National Disability Strategy 2011 and the PC's recommendation for an NDIS.

### *Action 1:*
### *Bring alive the National Disability Strategy*

Governments must not once more allow the energy to fail at the point of implementation. It needs to go actively on the front foot in supporting the rights of people with a disability by:

- continuing to acknowledge the appalling current situation, and its commitment to fixing it
- being proud of the National Disability Strategy and the UN CRPD
- supporting the actions and recommendations put forward in both the Shut Out report and the PC NDIS report
- announcing a comprehensive rights plan and implementation timetable for people with a disability that can be adopted and owned by the entire community
- introducing an interim plan to provide immediate relief to those most in need
- identifying ways to monitor the level of disadvantage, capture it and publish and advertise it on a regular basis
- embarking on a public affairs advertising campaign to raise awareness of and encourage action in support of Australia's National Disability Plan and our international commitments.

## *FACILITATION & CHOICE – Empowering the individual*

A very real and transparent catalyst in launching this rights plan is to fund it adequately and responsibly, based on outcomes and choice.

Government should not recoil from the additional cost of funding disability care and support, but rather should acknowledge the folly in not doing it sooner. It can put an end to the poor utilisation of large amounts of funding as well as assuming its share of responsibility to people with a disability and their families.

### *Action 2:*
### *Commit to a funding, support and governance mechanism that empowers individuals*

NDIS funding is overdue. It is now a necessity for Australia.

### *A. Expand and clarify commitment to the NDIS*

Government needs to fast-track the impact of the NDIS/NDIA by:

- releasing a timetable for transition to full roll-out of the NDIS, including a date for NDIA legislation and Board appointments
- committing to three years funding in forward estimates, as specified in the PC report
- committing to work on identifying NDIS launch sites
- providing immediate relief to those most in need, also as specified in the PC report
- seeking to achieve bipartisan support for the above commitments as a core responsibility of government.

### *B. Endorse and maintain the recommendations of the PC report for implementation*

The NDIS is recommended as a national scheme, funded as a core function of the Commonwealth government with certainty of funding based on need. The scheme is to be governed on prudential insurance-based principles. Further specific recommendations include:

- national eligibility criteria, assessment tools and arrangements for assessors
- entitlements to the full range of necessary individually tailored supports, based on the national assessment process
- genuine choice over how people's individual packages are met, including choice of provider and portability of entitlements across borders
- shift from block funding to individualised funding
- sophisticated collection and analysis of data to measure the outcomes and performance of the system
- a national research capacity
- common quality standards for providers, with competitive neutrality and with remuneration using efficient prices determined by the NDIA
- national and publicly available measures of the performance of service providers
- local area coordination and disability support organisations
- service provider and workforce development strategies.

In committing to the NDIS, government needs to acknowledge the specific recommendation of the PC in terms of the basic construct and governance of the NDIS (Chapter 9, and particularly Rec 9.11).

### *C. Develop and apply a purposeful risk management framework for implementation*

The PC documents in detail its rationale for these recommendations and describes the risks of not maintaining their integrity. These risks fall into a basket of adverse outcomes such as degeneration back into the current dysfunctional state system, demand or supply induced cost escalation, continued lack of equity, creation of an unnecessary bureaucracy, or simply not achieving the required outcomes.

In moving to implementation, government must institute a project management framework which militates against these risks. The risk management framework must be rigorous and targeted to appropriately identify and address potential slippage of the key principles described above.

### *D. Build sector-wide capacity to facilitate change*

A focus on building the capacity of the system; support organisations, as well as individuals and their families, will contribute to the realisation of choice for the individual and broader facilitation. This will involve:

- more extensive research into existing models to support individuals to make meaningful choices and plan effectively for the future
- evaluation of advocacy models and funding to identify strengths, weaknesses and gaps. A robust system requires individual and systemic advocacy. Individual advocacy supports vulnerable people during assessment and planning. Systemic advocacy operates as an important check and balance on the operation of the system as a whole
- prioritisation of the training and mentoring of executive and non-executive leaders. On its establishment, the NDIA in concert with the relevant peak body, should assess the training and mentoring needs of executive and non-executive leaders, and develop and execute a plan for addressing the identified gaps
- development of a national industry plan to facilitate the development of brokerage arrangements, while ensuring that support agencies are assisted where appropriate to develop their own plans for shifting to a NDIS
- development of a detailed workforce strategy and training program based on input, ideas, involvement of staff, individuals and their families
- strengthening the capabilities or proficiencies that will be required of organisations and the workforce in order to operate in the new environment. This includes: a human rights culture; customer and community focus; and integrated infrastructure.

## *INCLUSION – Equal access as a prerequisite for citizenhood*

The above commitments to the funding and principles of the NDIS would constitute a **necessary but not sufficient requirement** to achieve meaningful outcomes for people with a disability and their families.

In Sections 3 and 4 we discussed a 10-year vision for inclusion and citizenhood for people with a disability, and identified what needed to change for the main participants to realise this vision.

A well-functioning NDIS will facilitate some of that change, but fundamental change in mainstream services, infrastructure and cultural mores is a job for all governments.

Our first recommendation, **Bring alive the National Disability Strategy**, will set the scene, challenging the main barriers within mainstream services and broader culture.

### *Action 3:*
### *Actively pursue system and cultural change*

In order to achieve true social inclusion and citizenhood for people with a disability, a whole-of-government approach is required. A broader change plan needs to include an exploration of initiatives:

- agreeing and actively monitoring and reporting COAG access targets for people with a disability in transport, education, housing, health and aged care
- COAG agreeing and publishing regular information on the relative disadvantage of Australians with a disability
- COAG establishing an audit of all state and Commonwealth disability programs to assess alignment with moving towards an NDIS
- establishing employment incentives and support for people with a disability as well as employers
- actively engaging large businesses, corporate foundations and peak bodies such as BCA and ACCI to become agents for change – this could include, for example, the development of audit tools to promote better accessibility
- positive discrimination in some areas (similar to that given to small business, local content and environmentally friendly organisations)
- instituting meaningful small community awards to encourage local innovation.

Some of these proposals are specifically considered in the PC report.

### *RESULTS – Reporting on progress*

It is critical that detailed data be regularly collected and released describing the national social profile of Australians living with a disability, including data on diversity (ie sub-groups of people with a disability), measurements of access to key mainstream services, as well as availability of relevant specialist services. This data collection should be undertaken as part of the ABS's gathering of population statistics but designed to accurately reflect the social disadvantages imposed by disability across diverse groups. Data should be separately published and advertised.

### *Action 4:*
### *Begin and continue a process of outcome monitoring and public reporting*

Government and the NDIA have a significant role in assuring outcomes through building and implementing a strong monitoring and evaluation framework. This will involve reporting against typical proxy measures (ie input, process and output) but, more importantly, changes in outcomes at the individual level and shifts at the community level.

Through the NDIA, a national approach to monitor, review and evaluate the 10-year plan will move us closer to quantifying the unmet need across various areas. There is enormous potential in gathering and using data within a risk-based governance framework to boost transparency and accountability.

As part of this process, the NDIA ought to facilitate a robust, evidence-based approach to monitoring and reporting on outcomes – and continuous improvement in service delivery – at the support organisation level. A rigorous framework includes reviewing and improving services, tracking quality of life outcomes and learning from individuals (ie voice of the client) to inform strategic change, then reporting all relevant data to clients and in public, consolidated reports.

## Overarching recommendations

1. *Bring alive the National Disability Strategy.*
2. *Commit to a funding, support and governance mechanism that empowers individuals.*
    - *A. Expand and clarify commitment to the NDIS.*
    - *B. Endorse and maintain the recommendations of the PC report for implementation.*
    - *C. Develop and apply a purposeful risk management framework for NDIS implementation.*
    - *D. Build sector-wide capacity to facilitate change.*
3. *Actively pursue system and cultural change.*
4. *Begin and continue a process of outcome monitoring and public reporting.*

## Concluding remarks

The function of disability policy is to remove the barriers to full inclusion faced by people with a disability and their families in all aspects of Australian life – barriers in the built environment, barriers to public transport, barriers to participation in education, barriers to participation in the workforce, and barriers to full inclusion in social life, just to name a few. Disability policy at all levels of government should address the systematic dismantling of all of the barriers that prevent people with a disability from full, active citizenhood.

### *The National Disability Strategy*

The federal government's response to these barriers has been the development of the National Disability Strategy, a ten-year vision for addressing some of the challenges faced by people with a disability and their families in this country.

It is the first time in Australia's history that all governments – federal, state and local – have agreed to a unified national approach to improving the lives of people with a disability, their families and carers.

All levels of government have committed to undertaking work in the six areas of the National Disability Strategy – inclusive and accessible communities, rights protection, justice and legislation, economic security, personal and community support, learning and skills, and health and wellbeing.

### *The National Disability Insurance Scheme*

The NDIS adds additional leverage to the National Disability Strategy. It is about making sure people with a disability and their families get the support, care, therapy, equipment, early intervention and training they need to get out in the community and do what they want to do. The NDIS will transform the lives of people with a disability and their families in this country. It will ensure they are finally able to receive the support they need to reach their full potential.

But it is only part of the solution. It will not address the many other barriers people with a disability face in achieving full inclusion. In fact these areas will need to be addressed if the NDIS is to have the impact it is intended to have. The most obvious example is education. The NDIS will only be able to achieve its full potential if children and young adults with a disability get an education that adequately prepares them for later life. Without an education system equipped to meet the learning needs of all, children with a disability will not be able to reach their full potential. This will have a significant impact on the NDIS because these children will require a higher level of support in adulthood. It will also mean their participation in the wider Australian economy will be limited.

The NDIS is a necessary but not sufficient condition for the delivery of better disability policy outcomes. It is not of itself the end, it is the means – and therefore **the NDIS is the most important enabler of a better life**.

# *Disability thought leadership participants*

*PwC takes full responsibility for the ideas expressed in this paper, which have been distilled from the range of opinions and views expressed by the thought leadership group members. Participants were invited to join the group on the basis of their expertise rather than as representatives of particular interest groups or government departments. All discussions were conducted under the* ***Chatham House Rule****, and the views contained in the paper should not be interpreted as being endorsed by either the individuals who participated or by their organisations.*

**The Honourable John Della Bosca**

Chair, Thought leadership group
National Campaign Director
Every Australian Counts Campaign

**Dr Ken Baker**

Chief Executive
National Disability Services

**David Barbagallo**

Chief Executive
Endeavour Foundation

**Prof. Christine Bigby**

Director of Postgraduate Programs
Department of Social Work and Social Policy
La Trobe University

**Bruce Bonyhady AM**

Chairman
Yooralla

**David Bowen**

Chief Executive
Lifetime Care and Support Authority

**A/Prof. Fiona Kumari Campbell**

Deputy Head of School
(Learning & Teaching Scholarship)
Griffith Law School

**Kirsten Deane**

Executive Director
National Disability and Carer Alliance

**Richard Dent**

Chief Executive
E.W. Tipping Foundation

**Gordon Duff**

Principal Adviser, Industry Development
National Disability Services

**Lesley Hall**

Chief Executive
Australian Federation of Disability Organisations

**Patrick Maher**

Chief Operating Officer
National Disability Services

**Marita Walker**

Chief Executive
Perth Home Care Services

**Rob White**

Chief Executive
Cerebral Palsy Alliance

**Robbi Williams**

Chief Executive
Julia Farr Group

**Alan Woodroffe**

Senior Manager, Policy Services and Review
Transport Accident Commission

## *PwC participants*

**John Walsh AM**

Partner
Health Actuarial

**Chris Bennett**

Partner
Government Sector Leader

**James van Smeerdijk**

Partner
Economics and Policy

**Luke Sayers**

National Managing Partner

**Sarah Johnson**

Director
Health Actuarial

**Monica Iglesias**

Manager
Health Consulting

***pwc.com.au/industry/government***

## Contacts

**John Walsh AM**
*Partner*

Phone: +61 2 8266 3205
Fax: +61 2 8286 3205
john.e.walsh@au.pwc.com

**Chris Bennett**
*Government Sector Leader*

Phone: +61 3 8603 2337
Fax: +61 3 8613 2403
chris.bennett@au.pwc.com

### Australian Capital Territory

**Roger Beale AO**
Phone: +61 2 6271 9256
Fax: +61 2 6271 9856
roger.beale@au.pwc.com

### New South Wales

**Mark Driessen**
Phone: +61 2 8266 5466
Fax: +61 2 8286 5466
mark.c.driessen@au.pwc.com

### Queensland

**Robert Hubbard**
Phone: +61 7 3257 8597
Fax: +61 7 3031 9303
rob.s.hubbard@au.pwc.com

### South Australia

**Mark Coughlin**
Phone: +61 8 8218 7760
Fax: +61 8 8218 7894
mark.coughlin@au.pwc.com

### Victoria

**James van Smeerdijk**
Phone: +61 3 8603 4814
Fax: +61 3 8613 5318
james.vs@au.pwc.com

### Western Australia

**Stephanie Allen**
Phone: +61 8 9238 5121
Fax: +61 8 9488 4693
stephanie.allen@au.pwc.com