



Australian Government

# SHUT OUT:

The Experience of People with Disabilities  
and their Families in Australia

**National Disability Strategy Consultation Report  
prepared by the National People with Disabilities and Carer Council**

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The analysis presented in this report reflects the submissions received by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) in response to the National Disability Strategy consultation process.

All direct quotes in this report are excerpts from submissions and material obtained during the consultation process. It is, however, important to note that neither FaHCSIA nor the National People with Disabilities and Carer Council was able to verify the accuracy of the submissions or consultation comments. Nor should the analysis be read as representative of all Australians with disabilities, because participants and respondents were self-selected. FaHCSIA made every effort to obtain permission to publish all direct quotes. The submissions contain the ideas and thoughts of those who chose, or who were able, to provide a submission, and there may be other individuals, groups or government bodies that did not respond but may have other ideas or experiences.

The guidelines for submissions as set out in the consultation discussion paper were broad, which permitted discussion of a wide range of ideas, issues and solutions. But the absence of an issue or idea in a submission does not indicate that the issue is not important to the submitter, only that they did not choose to write about it.

This report should not be read in isolation, nor will it be the only source of data to inform the development of the National Disability Strategy. Rather, the report is a useful way of bringing together the voices of those people with disabilities, their families, friends and carers and the organisations that support them who provided submissions and participated in consultations. By identifying and discussing the issues in this way, new ideas and solutions may be discovered. This information, in conjunction with other evidence and data, will inform the development of the National Disability Strategy.

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# FOREWORD



Ideally, we want to live in a dignified and simplified society where we have the confidence and self esteem to speak our mind and have the opportunities that everyone has.

The sentiments expressed in this submission—the right to be treated with dignity and to have the same opportunities as other members of the Australian community—should not be too much to ask.

But many Australians with disabilities, along with their families, friends and carers, are still experiencing systemic disadvantage. The national ideal of a ‘fair go’ is still only imperfectly extended to people with disabilities. We want our National Disability Strategy to tackle that disadvantage.

Hundreds of voices from across Australia contributed to consultations for the strategy. The people who participated are, just like all other Australian citizens, individuals with their own needs, abilities, ambitions and priorities. They are united only by the experience of living with disability.

Yet a consistent message from their contributions is the desire to have the same opportunities as everyone else for a fulfilling and productive life. Many said they face a constant struggle to obtain what the rest of the community would consider to be an ordinary life. They do not want special treatment—they just want the barriers removed so they can get on with living.

The task that falls to us is to make the political, social and economic changes necessary to enable this to happen. We have been told we need to tackle issues and barriers around disability services, we need to ensure an adequate standard of living for all our citizens, and we need a society in which all people are included and are supported as citizens and leaders in the community.

This work has begun in the 19 months we have been in government. We are investing over \$5 billion in funding over five years for specialist disability services through the National Disability Agreement, representing a significant growth in funding compared to previous agreements. The 2009-10 Budget delivers substantial reform of the pension system, which will improve adequacy, security and flexibility for people receiving Age Pension, Disability Support Pension and Carer Payment and related payments.

We were one of the first countries to ratify the *United Nations Convention on the Rights of Persons with Disabilities* as part of the Australian Government’s broader long-term commitment to improving the lives of people with disabilities, their families, friends and carers.

In partnership with state and territory governments, the Australian Government is developing a National Disability Strategy, which will be informed by the views in this report.

We want the National Disability Strategy to map out what we need to do to start fixing problems. This will not be easy and it will take time. We have therefore asked for the strategy to be delivered to government by mid-2010. We are particularly interested in the solutions and creative ideas summarised in this report and the ideas that have come from people who live with disability.

We welcome this report and would like to thank the many people who attended public forums and focus groups and took the time and effort to write submissions, despite their busy lives.



*Jenny Macklin*

**The Hon Jenny Macklin MP**  
Minister for Families, Housing, Community Services  
and Indigenous Affairs



*Bill Shorten*

**The Hon Bill Shorten MP**  
Parliamentary Secretary for Disabilities and Children's Services,  
Parliamentary Secretary for Victorian Bushfire Reconstruction



# PREFACE

Many people in the community believe disability is someone else's problem. They do not believe disability will touch their lives, and give little thought to the experience of living with disability, or caring for someone with a disability. Without first-hand experience, they hold on to the belief that at least things are better than they used to be.

The stories you will find in this report will challenge those beliefs.

For many years people with disabilities found themselves shut in—hidden away in large institutions. Now many people with disabilities find themselves shut out—shut out of buildings, homes, schools, businesses, sports and community groups. They find themselves shut out of our way of life.

As this report sadly illustrates, Australians with disabilities are among our nation's forgotten people. But it is time for their stories to be heard—and acted upon.

I was appointed Chair of the National People with Disabilities and Carer Council in September 2008. The primary role of the council is to provide expert advice and information to the Australian Government on the development and implementation of a National Disability Strategy. Through its membership, the council provides a means for people with disabilities, and their families, friends and carers, to have an ongoing voice in the development of the policies and strategies that affect their lives.

One of my first jobs as chair was to begin the national conversation about disability and coordinate public consultations on the National Disability Strategy. It was my privilege to attend every consultation held in capital cities across Australia.

What I heard was both intensely moving and profoundly shocking. We live in one of the wealthiest countries in the world and yet all too often people with disabilities struggle to access the very necessities of life—somewhere to live, somewhere to work. All too often they are unable to access education, health care, recreation and sport—the very things most people in the community take for granted. They are denied access to kindergartens, schools, shopping centres and participation in community groups. They are often isolated and alone. Their lives are a constant struggle for resources and support.

Aboriginal and Torres Strait Islanders with disabilities face a particular battle. They experience the dual disadvantage of prejudice because of their disability and racism because of their heritage. Disability services rarely understand their cultural needs, while mainstream services rarely understand the nature and experience of disability.

But the consultations and submissions also showed that people with disabilities are determined and strong. They have fought hard to achieve their goals. They have refused to take no for an answer.

People with disabilities and their families, friends and carers are clearly resourceful and innovative. They find ways to meet the challenges that they face, though the solutions are rarely ideal. Through this report, I want to share with you some of their ideas—big and small. They will surely inspire our leaders, policy makers and communities to work towards real and lasting change.

The process of change has, in some areas, already begun. Changes to the Disability Support Pension, announced after the consultation process had concluded, are particularly welcome. The additional funds and reforms announced as part of the National Disability Agreement represent important steps forward.

I would like to personally thank each and every person who took the time to write a submission or who attended consultations across the country. Their readiness to reveal personal details was both remarkable and encouraging. It was clear to me that people were willing to do so only in the hope that they would finally see change. I want those people to know that their voices were heard.

I came away from those consultations both angry and sad. But most of all, I came away determined.

Australians with disabilities have been waiting for many years for change. They cannot and will not wait any longer. The National Disability Strategy represents an important part of the long journey to ensure people with disabilities are finally truly a part of the Australian community.

I hope you will join me and be part of that journey.



A handwritten signature in black ink that reads "Rhonda Galbally". The signature is written in a cursive, flowing style.

Dr Rhonda Galbally AO  
Chair, National People with Disabilities and Carer Council



Disability is characterised by desire for positive change and striving for emancipation and flourishing. It is seen every day amongst people living with disability. It is active hope.

**We desire a place within the community!** This place is not just somewhere to lay down our heads, but a place which brings comfort and support with daily living, friendship, meaningful work, exciting recreation, spiritual renewal, relationships in which we can be ourselves freely with others. And out of this great things may flourish.

Perhaps we will begin to feel better about ourselves, to come to know ourselves as honoured, respected, accepted, yes, loved. To be healed from shame, feeling unworthy, undesirable, ugly, difficult, not smart enough, not sporty enough, not lovely enough. And perhaps we might be freed from our terrible daily fears that it all won't last, that more rejection is written into our lives. Maybe our dreams will no longer be filled with the traumatic fear of others pushing us around.

Perhaps a time will come when we no longer have to protect ourselves from loss and can feel that this place is the place of creation, of re-creation, co-creation. Perhaps then our loneliness will fade. Perhaps then we will belong and our gifts (perhaps meagre, perhaps spectacular) freely shared. And from there will flow all the delights and tragedies of a life lived in the community, shaped not by exclusion and oppression but by everyday ordinariness (whatever that might be)!

— National Disability Strategy submission (emphasis added)

# 1 EXECUTIVE SUMMARY



Until the concept of disability disappears and is replaced by a society that is structured to support everyone's life relatedness and contribution—until that day my life and opportunities and the lives of every other person who carries the label 'disabled' depends on the goodwill of people in the human service system. Goodwill is no substitute for freedom.

Many of the large institutions that housed generations of people with disabilities—out of sight and out of mind—are now closed. Australians with disabilities are now largely free to live in the community. Once shut in, many people with disabilities now find themselves shut out. People with disabilities may be present in our community, but too few are actually part of it. Many live desperate and lonely lives of exclusion and isolation. The institutions that once housed them may be closed, but the inequity remains. Where once they were physically segregated, many Australians with disabilities now find themselves socially, culturally and politically isolated. They are ignored, invisible and silent. They struggle to be noticed, they struggle to be seen, they struggle to have their voices heard.

What you will read in this report is their attempt to break down the walls of silence and finally have their story told.

In late 2008, the Australian Government released a discussion paper asking the community to respond to a series of questions about their experience of disability (see Appendix A). The consultations were intended to inform the development of a National Disability Strategy. Reflecting the Australian Government's commitment to social inclusion, the aim of the National Disability Strategy is to ensure that people with disabilities have the opportunity to fully participate in the economic, social and cultural life of the nation. Developed by the Commonwealth in partnership with state and territory governments, the National Disability Strategy offers an unprecedented opportunity to articulate a clear vision and to marshal resources towards the achievement of common goals. It will galvanise and direct coordinated action between all levels of government to close the gap between the lived experience of people with disabilities and the rest of the Australian community.

More than 750 submissions were received in response to the discussion paper, more than half of which were from individuals and the remainder from a range of organisations (see Appendix B). This overwhelming response from ordinary Australians, so often excluded from the process of policy development, is an important indication of the depth of feeling among people with disabilities and their families, friends and carers. They have long called for change. Now they want to see it.

More than 2,500 people also attended consultations in capital cities in every state and territory of Australia, as well as in regional and remote areas (see Appendix C). These sometimes fiery, often sad and occasionally funny meetings provided unique insight into the day-to-day struggles of Australians with disabilities.

All direct quotes in this report are drawn from the submissions and material obtained during the consultation process. In some cases identifying information has been removed to ensure anonymity, but otherwise all quotes preserve the original words of the writer or speaker.

While the issues raised were many and varied, a clear picture emerged from the consultations and submissions. People with disabilities may be present in the community but most do not enjoy full participation in it. Discrimination and exclusion are frustrating features of daily life. People in wheelchairs cannot access the public facilities taken for granted by others in the community, such as playgrounds, swimming pools, cinemas, restaurants, hotels and cafes. Children with disabilities find themselves excluded from local kindergartens and schools. Qualified and competent candidates for jobs are rejected because of their disability. People with mobility aids have difficulty regularly accessing public transport. People with various disabilities are unable to access the aids, equipment and technology essential to their daily functioning, and are unable to access the support required to get them out of bed in the morning.

The general public believes much has changed in the past 30 years. And it is true that important gains have been made. But the prosperity of recent times has not been shared equally. People with disabilities feel forgotten. The tales told in the submissions are heart-wrenching and distressing. Page after page tells of suffering and despair. There is also enormous frustration and anger at a lack of progress after so long.

But there were also tales of survival, of immense personal strength and determination. Again and again, people with disabilities and their families, friends and carers demonstrated their resilience. These were tales of success. Many people demonstrated considerable courage in telling their stories in submissions and at public consultations. Their willingness to reveal personal details in such a public manner was an indication of their deep desire and determination to see change.

Many people described their lives as a constant struggle—for support, for resources, for basic necessities, for recognition. Over and over participants made the comment that it should not require such extraordinary effort to live an ordinary life.

## MAIN FINDINGS—AN ANALYSIS OF THE SUBMISSIONS

The discussion paper asked people with disabilities and their families, friends and carers to identify the main barriers to their full participation in the economic and social life of the community. The following table summarises their responses.

Area where barriers experienced	Percentage of submissions <sup>1</sup>
Social inclusion and community participation	56
Disability services	56
Rights, justice and legislation	39
Income support and the cost of disability	37
Employment	34
Accommodation	32
Families and carers	30
Education	29
Transport	29
Health and wellbeing	29
Built environment	27
Disability services—workforce issues	21
Aids, equipment and assistive technologies	20

### Social exclusion and discrimination

A lack of social inclusion and the multiple barriers to meaningful participation in the community faced by people with disabilities were the most frequently raised issues in the submissions and consultations. More than half the submissions received (56 per cent) identified exclusion and negative social attitudes as critical issues. People with disabilities and their families, friends and carers reported daily instances of being segregated, excluded, marginalised and ignored. At best they reported being treated as different. At worst they reported experiencing exclusion and abuse, and being the subject of fear, ignorance and prejudice.

People with disabilities believe little progress has been made in challenging prevailing attitudes towards disability. Submissions suggested that there are still widespread misconceptions and stereotypes informing the attitudes and behaviour of service providers, businesses, community groups, governments and individuals.

<sup>1</sup> As some responses referred to multiple ideas, analysis of the responses enabled multiple ideas to be coded. There are therefore more themes than submissions and percentages add up to more than 100 per cent.

As a result, discrimination is a feature of daily life for many people with disabilities and their families. More than 39 per cent of submissions identified discrimination and rights as a vital issue, with one submission noting,

“ Virtually every Australian with a disability encounters human rights violations at some point in their lives and very many experience it every day of their lives.

Submissions argued that discrimination is both systemic and systematic, entrenched in the everyday practices of government, businesses, community groups and individuals.

“ In this day and age, imagine if a person was told that they could only go to ten cinemas in Australia and to one of three sessions a week because of their gender, cultural background or religious beliefs. But as a deaf person, that is what I face. I am very limited in where I can go and when, to access things that other people take for granted.

One submission told the story of a child care centre that refused to provide care for a child with an intellectual disability. Another told of a young man with a disability denied a vital organ transplant because of his disability (but who was then told he would, of course, be welcomed as a donor).

Proposed solutions varied widely. Some saw the role of the National Disability Strategy as establishing a social inclusion framework to underpin all policies and programs. Many called for an end to segregated services and options for people with disabilities, and their families, friends and carers, which people believed only reinforced and exacerbated prevailing attitudes. They sought a more integrated approach to support and greater availability of choice. The invisibility of people with disabilities and the dearth of independent advocacy and leadership opportunities also means too few people with disabilities have meaningful opportunities to contribute to the process of political and policy change.

### **Lack of services and support**

Disability services are intended to provide people with disabilities and their families, friends and carers with the assistance they need to fully participate in daily and community life. More than half of the submissions received during the consultation process (56 per cent) said that services and programs act as a barrier to, rather than a facilitator of, their participation. The disability service system was characterised as broken and broke, chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need. Services were unavailable or infrequent, unaffordable or of such poor quality as to be of little benefit. Respondents felt that more effort went into rationing services than improving them. Many said that the system is characterised by a one-size-fits-all approach that offers very little choice or

flexibility. Programs and services were built around organisational and system needs rather than the needs of clients. In a democratic country as wealthy as Australia, many found it absolutely unacceptable that they are unable to access the support and services required to achieve even a basic quality of life.

Importantly, many argued that the service system is so fundamentally flawed as to be beyond bandaid solutions, requiring a paradigm shift to deliver lasting change. Many submissions suggested that both systemic reform and greater resourcing are essential. They argued that the service system needs to move away from a welfare model of service provision to a person-centred approach that sees services not as charity but as a social investment in realising the potential of people with disabilities.

### **The need for a lifetime care and support scheme**

A significant number of submissions argued that the fundamental reform required to achieve lasting change in the disability service and support system should be extended to the funding of the system itself. These submissions made it clear that despite recent commitments to an increase in resources, the system is unable to meet current need and has limited capacity to meet anticipated increases in demand. Respondents also spoke of a pressing need to address inequities in the system, which result in people with disabilities receiving different levels of support depending on how their disability was acquired. According to these submissions, the only answer to the problems confronting the system is to create a model of funding in which resources are available irrespective of changes to the economic climate or variability in political will.

While details varied, these submissions argued that a lifetime care and support scheme would remove existing inequities and provide the resources needed to ensure people with disabilities are able to reach their full potential and live as independently as possible.

### **The employment experience of people with disabilities**

The opportunity for meaningful employment is essential to not only an individual's economic security but also their physical and mental health, personal wellbeing and sense of identity. Unfortunately too few people with disabilities are able to access meaningful employment. Negative attitudes and misconceptions about disability means few employers—whether government, non-government or corporate—appear willing to employ anyone with a disability. In some cases there was clear discrimination, with qualified candidates reportedly sidelined solely because of their disability.

People with a history of mental illness or an intellectual disability appeared to be particularly stigmatised. In other cases, employers seemed unwilling to employ a person with a disability due to misconceptions about the cost of modifications and adaptive technology.



Despite having the ability and willingness to work, many people with disabilities reported frustration at their reliance on the Disability Support Pension. The high cost associated with living with disability relative to the level of the pension was seen as restricting the ability of people to live independently and enjoy a decent standard of living. People with disabilities and their families, friends and carers reported living lives of ‘fear and desperation’, despised by many in the community for their reliance on the pension, yet unable to access the support they required to move off it. Gripped by poverty, the cost of basic necessities was sometimes even beyond them. While the consultation process concluded before the recent Budget announcement of an increase to the Disability Support Pension and changes to eligibility rules, these changes were welcomed by many in the community as an important step in addressing the high costs associated with living with a disability.

### **Negotiating the built environment and accessing information**

More than 27 per cent of submissions said that lack of access to buildings and facilities is a barrier to full participation in the community, while 29 per cent identified lack of access to transport as a significant barrier to inclusion. There was considerable frustration at the slow pace of legislative and policy change to ensure universal design principles are included in the development of all new public and private buildings, as well as the painfully slow process of modifying existing structures. There was frustration, too, at the slow pace of transport reform, which in some cases is being carried out over a 30-year timetable. Many submissions noted that lack of access to public transport often forces heavy reliance on the expensive and sometimes unresponsive taxi system.

But for some people with a sensory impairment or intellectual disability, access issues go beyond structural features. Submissions noted that for these groups, access to information remains problematic—information is still rarely provided in alternative accessible formats, including plain English versions.

### **The education experience of people with disabilities**

Education determines more than a child’s economic future—it is also critical to a child’s social and emotional development, to establishing a sense of identity and a sense of place in the world. It is therefore of considerable concern that 29 per cent of submissions reported frustration with the education system. Most submissions noted that the system has little capacity to meet the needs of students with disabilities. The system was characterised as chronically under-funded and staffed by teachers who received little or no training with regard to disability. Submissions reported widespread ignorance and fear of disability and little or no promotion of the benefits of inclusion. Parents reported particular frustration at their lack of choice of educational setting and

the desperate lengths they were forced to go to in order to ensure their child had basic needs addressed. Most sadly reported that they believed their child with a disability was only receiving 'second best'.

### **The social experience of disability**

Social isolation emerged as an important issue confronting people with disabilities. The Australian Bureau of Statistics estimates that 15 per cent of people with disabilities aged 15 to 59 (or 287,500 individuals) live alone compared to 6.8 per cent of people without disabilities.<sup>2</sup> For some people with disabilities, the years of isolation and exclusion have had a profound impact on self-worth and self-esteem.

Submissions from families, friends and carers and the organisations that represent them were characterised by their great love for the people they care for. Many detailed the extraordinary lengths they go to every day to ensure their loved one has the same opportunities that others in the community take for granted. But the submissions also demonstrated that the experience of caring for someone with a disability is often a lonely one. Family, friends and other carers reported feeling abandoned by both government and the community and felt there was too little support for their all-important role. Many expressed frustration that they alone were left to fill the gaps in the service system. As a result, many argued that a significant proportion of their needs would be met if appropriate services, programs and supports for people with disabilities were routinely available. Submissions argued that greater support and flexibility for families and carers would ensure that they were able to continue in their important role.

### **The way forward—implications for the development of the National Disability Strategy**

The National Disability Strategy represents the first time in this country that disability policy will be underpinned by a whole-of-government, whole-of-life approach. In outlining a high-level strategic vision, submissions argued that the strategy must ensure that there is coordinated and comprehensive planning across all portfolios and between all levels of government. In developing the strategy, the government must consider how current disability and mainstream policies, programs and services operate, how they can work together more effectively and what new initiatives are needed. Importantly, the strategy must recognise the complexity of people's lives and the intersection and interdependence of many areas.

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<sup>2</sup> Australian Bureau of Statistics, 2003, *Disability, Ageing and Carers: summary of findings*, cat. no. 4430.0, ABS, Canberra, p. 20.

From its review of submissions and consultation material, the National People with Disabilities and Carer Council believes that the National Disability Strategy should act as an overarching policy statement, setting the national view, establishing future direction and identifying priorities for people with disabilities and their families, friends and carers. It should address four strategic priorities:

- increasing the social, economic and cultural participation of people with disabilities and their families, friends and carers
- introducing measures that address discrimination and human rights violations
- improving disability support and services
- building in major reform to ensure the adequate financing of disability support over time.

While details varied, most submissions agreed that the strategy should consider the following key features:

- adoption of a coordinated national approach to enhance consistency across jurisdictions
- development of underlying principles that reflect the *UN Convention on the Rights of Persons with Disabilities*. Many submissions made it clear they expect the National Disability Strategy to realise the rights enshrined in the Convention. Without a strong strategy, many participants feared that the Convention would fail to change the lives of Australians with disabilities and become just another piece of meaningless rhetoric
- creation of an Office of Disability to coordinate efforts across portfolios and between levels of government
- implementation and monitoring of policies under the strategy by each level of government and all government agencies, with clear outcomes and performance measures
- provision of funding increases to advocacy and other non-government agencies to participate in monitoring and evaluation of the strategy.

The findings contained in this report will now feed directly into the development of the National Disability Strategy. Australian governments will continue to work throughout 2009-10 on the strategy with the advice of the National People with Disabilities and Carer Council and other stakeholders. Critical thinkers and subject experts will be brought together to develop innovative strategies and actions to tackle identified priorities in each area along with appropriate outcomes and targets. And most importantly, an evaluation, monitoring and reporting process will be developed as a means of tracking the progress of the strategy to ensure real and meaningful change is achieved.

## CONCLUSION

The closure of institutions and the promise of community inclusion was one of the great social policy changes of the 20th century. But the social and economic segregation that has followed is harder to dismantle. Closing doors is one thing. Making fundamental changes to our policies and programs, and changing the way we think, is another. But as the participants in this consultation told us, they can no longer accept anything less.

People with disabilities want to bring about a transformation of their lives. They want their human rights recognised and realised. They want the things that everyone else in the community takes for granted. They want somewhere to live, a job, better health care, a good education, a chance to enjoy the company of friends and family, to go to the footy and to go to the movies. They want the chance to participate meaningfully in the life of the community. And they are hopeful. They desire change and they want others in the community to share their vision. They recognise that governments cannot work in isolation and they want others to see the benefits of building more inclusive communities.

For years people with disabilities have been excluded, forgotten and ignored. Now they demand to have their voices heard. As one respondent noted, admitting failure is the first step in fixing things. This report details the way things are broken. Now begins the long process of repair.

## 2 SUMMARY AND ANALYSIS OF SUBMISSIONS AND CONSULTATIONS —

### THE EXPERIENCE OF PEOPLE WITH DISABILITIES AND THEIR FAMILIES, FRIENDS AND CARERS



People with a disability want to live in a society where they are treated with respect, dignity and importantly with equality, and not as ‘poor things’ nor merely as recipients of services. Additionally they do not want to be segregated as ‘people with disabilities’.

#### 2.1 OVERVIEW

The guidelines set out in the National Disability Strategy Discussion Paper were deliberately broad, which allowed a wide range of ideas, issues and solutions to be raised and discussed. Despite the considerable number of submissions and large number of participants at community consultations, there was striking consistency in the issues raised. Fifteen main issues were identified and grouped under six headings.

The following summary reflects the experiences and ideas of those who were able or who chose to provide a submission or attend consultations. There may be other individuals, groups or bodies that did not respond and who may have other ideas or experiences. The ordering of issues does not reflect their relative importance, or the weight each will be assigned in the National Disability Strategy. It is simply an effective means of summarising the content of submissions.

More than 750 submissions were received in response to the release of the discussion paper. More than half the submissions were from individuals, with others coming from organisations (31 per cent), peak bodies (6 per cent), local governments (4 per cent), state and territory governments (3 per cent), the Australian Government, and individual members of parliament.

Many submissions did not identify a specific impairment. Of those that did, the most commonly reported were:

- intellectual disability (9 per cent)
- physical disability (9 per cent)
- mental illness (7 per cent)
- deafness/hearing impairment (6 per cent)
- blindness/vision impairment (6 per cent).

## 2.2 'EXCLUDED AND IGNORED'— THE EXPERIENCE OF EXCLUSION AND DISCRIMINATION

### 2.2.1 SOCIAL EXCLUSION AND LACK OF COMMUNITY PARTICIPATION



There are still widespread misconceptions and stereotypes about people with a disability. These include that they are a danger, a burden, and a threat. It is not uncommon to hear people express the view that people with a disability would be better off in institutions with people of their own kind. There also appears to be a common belief that people with a disability are not able to make a significant contribution to the community, and that they are somehow not of equal value as human beings and members of the community. Many people have low expectations of people with a disability, believing that they cannot learn or are not able to do anything useful. They are often denied opportunities to experience life, to explore their potential and achieve success, because it is assumed that their potential is limited. It is often stated that people with a disability are tolerated in the community, but tolerance is not acceptance and genuine inclusion.

In a society where the values that predominate are power and wealth, physical prowess and beauty, intelligence, competition, autonomy and self-control, many people with a disability are marginalised and devalued. It could well be that many people are fearful about engaging with and including people who live with a disability as a result of a lack of knowledge, and that people with a disability are treated as 'the other' rather than involved.



If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses, and if the community was completely accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have Spina Bifida.

Lack of social inclusion and the multiple barriers to meaningful participation in the community faced by people with disabilities were the most frequently raised issues in the submissions and consultations. More than half the submissions received (56 per cent) discussed the experience of exclusion and the impact of negative social attitudes on the lives of people with disabilities and their families, friends and carers.

These submissions made it clear that very little progress has been made in challenging prevailing myths and stereotypes about people with disabilities. They still find themselves the subjects of fear and ignorance, regarded as burdens or objects of pity.



More often than not, people with disabilities are seen as recipients of services and a burden rather than equal members of the community.

These misconceptions continue to inform both attitudes and behaviour, resulting in exclusion and discrimination. As one respondent suggested,



Societal attitudes have not developed in isolation from the ways that we have historically responded to people with disabilities. Nor can they be adequately addressed without changing the way we continue to respond to people with disabilities. It can be argued that negative attitudes, myths, stereotypes are both the cause and result of social exclusion for people with disabilities through service practices that segregate and congregate people with disabilities.

The submissions made it clear that negative attitudes are both powerful and entrenched and, as a result, exclusion is both systematic and systemic. Widespread misconceptions and ignorance about people with disabilities are still informing the attitudes and behaviour of government, service providers, businesses and individuals in the community. People with disabilities, and their families, friends and carers, reported daily instances of being segregated, excluded and ignored.

As one submission noted,



The greatest barrier facing people with Down Syndrome is not their intellectual disability but confronting negative attitudes, overcoming outdated stereotypes and challenging the limitations placed on them by others. What they lack is not ability but opportunity. The National Disability Strategy represents a significant opportunity to break down the barriers and create the kinds of opportunities people with Down Syndrome need to live the ordinary life to which they aspire.

When not regarded as invisible, many reported frustration at the patronising way they were treated. There was significant resentment at constantly being regarded as passive recipients of charity who should demonstrate considerable gratitude for whatever meagre offerings they received.

These entrenched and widespread attitudes mean that many people with disabilities, and their families, friends and carers, experience considerable difficulty accessing the kinds of services others in the community take for granted. Many submissions outlined in detail the barriers people faced when trying to access services to meet basic health, education, social and recreational needs. The examples were many—the Neighbourhood House that only offered segregated programs for participants with disabilities, the child with a disability refused kindergarten enrolment, the young man with autism unable to find a school willing to include and support him, the doctor's office with nothing but a kitchen table suitable for the examination of a woman with a disability. One submission told the story of a community recreation program unwilling to include a child with an intellectual disability in a gymnastics class.



The gym offered a separate class for kids with disabilities. I asked one of the teachers whether it would be possible for my daughter to attend one of the other mainstream classes. She frowned and looked concerned, and said that was why they had created the separate class. I said she was perfectly capable of joining in with the other girls. She said 'Well that's OK for your daughter but if we let her in we will have to let everyone else in'. These are not elite gymnasts. They are little girls jumping around in leotards having fun on a Saturday morning.



Most respondents were realistic in their assessment of what could be achieved. People with disabilities are all too aware of the impact of their impairment. They live with it every day. But what they are clearly angry about is the way that impairment interacts with the social and physical environment. They do not want mountains to be moved. But they do want to be able to go to the library or the movies. As one respondent noted,

“ I do not expect to get access to the pyramids or Uluru but I do want to get into all of the library and all of the community centre.

And another said,

“ How we view impairment and disability has changed dramatically over recent years ... although the impairment a person has is a reality, the disablement is caused by environmental and social barriers.

### Proposed solutions

Proposed solutions varied widely. Some felt that the National Disability Strategy had an important role to play in establishing a social inclusion framework that could underpin all policies and programs. Many called for an end to segregated services and options for people with disabilities, and their families, friends and carers, which they believed only reinforced and exacerbated prevailing attitudes. They suggested instead a more integrated approach to policies, programs and services. Others suggested broadening the aims of disability-specific programs and services from function and independence to social inclusion and community participation. Still others emphasised the importance of choice. Many suggested addressing the invisibility of people with disabilities in the community through education and awareness campaigns.

## 2.2.2 DISCRIMINATION AND HUMAN RIGHTS VIOLATIONS

In 2008, the Australian Government ratified the *UN Convention on the Rights of Persons with Disabilities*. But as many submissions and consultation participants were quick to point out, ratification does not ensure compliance. The gap between the principles enshrined in the legislation and the lived experience of many people with disabilities was a recurring theme—in fact, the issue of rights and discrimination was raised in 39 per cent of submissions. People with disabilities reported experiencing discrimination in every aspect of their lives, with one submission noting:

“ Persons with disability are subject to multiple and aggravated forms of human rights violations, including the neglect of their most basic survival related needs. These human rights violations do not only occur in far off places that lack enlightened legislation and policies, or the resources needed to meet basic needs. They occur every day, in every region, of every state and territory in Australia. Virtually every Australian with disability encounters human rights violations at some points in their lives, and very many experience it every day of their lives.

In 2009, in one of the most enlightened and wealthiest nations in the world, it is possible for persons with disability to die of starvation in specialist disability services, to have life-sustaining medical treatments denied or withdrawn in health services, to be raped or assaulted without any reasonable prospect of these crimes being detected, investigated or prosecuted by the legal system, and to have their children removed by child protection authorities on the prejudiced assumption that disability simply equates with incompetent parenting.

Submissions argued that discrimination is both systemic and systematic, entrenched in the everyday practices of government, businesses, community groups and individuals. The majority of complaints received by the Australian Human Rights Commission in 2007-08 involved discrimination on the basis of disability. People with disabilities and their families, friends and carers face discrimination in all areas including education, employment, health care and housing. Many detailed the multiple barriers they experience every day trying to access facilities and services that everyone else in the community takes for granted.

“ As a widower with two intellectually disabled children, I had enrolled one of them (aged three years) in a child care centre so I could return to work. After two to three weeks when I took this child to the centre on my way to work I was told at the door that he could no longer attend the centre from that day. The reason given was that he was intellectually disabled with behavioural problems that did not suit the environment. I had explained the situation fully prior to his enrolment. I then had to seek an alternative means of support for that day and on a permanent basis.

“ There would be community outrage if we said that we won't allow people onto all of our public transport for the next 25 years because of their cultural background, gender or religious beliefs. Or, that these people can only travel on 50

per cent of our buses in Australia up to 2012. There would be a national and international outburst of rage and non-acceptance if either of these two proposals were made. Yet this is exactly what is contained in regulatory legislation in Australia today. People in wheelchairs continue to have to wait at bus stops, in all types of weather, while others get onto the bus because, on average, every second bus in Australia is not accessible. This continues to happen every day in all capital cities around Australia and thousands of Australians with disabilities have no other option but to wait for the next bus and just hope that it will be accessible. Where is the community outrage?

The submissions also made it clear that one important reason discrimination had become so systematic and entrenched was the lack of redress. Submissions noted that legislation protecting the rights of people with disabilities is inconsistent across jurisdictions, and there is a remarkable lack of monitoring and enforcement of standards and no effective independent complaints process. A number of submissions argued that the process to lodge a complaint under the *Disability Discrimination Act 1992* (Cwlth) is onerous and relies too heavily on individuals being prepared and able to take part in lengthy and costly legal proceedings. The significant personal and financial cost involved in making a complaint prevents many from taking their concerns forward.

A number of submissions also argued that the invisibility of people with disabilities in the community hinders the fight against exclusion and discrimination. Many believed Australians are generally unaware and would be truly shocked at the quality of life of many people with disabilities and their families, friends and carers. These submissions argued that there is a pressing need for greater independent advocacy for and by people with disabilities to ensure their stories are told and their voices heard. They also called for the creation of more opportunities for leadership development for people with disabilities to enable them to participate in the political and policy process.

Other issues raised by submissions included:

- concern over the practice of relinquishing children with disabilities to state care as a last resort to ensure access to services
- the over-representation of people with disabilities in the criminal justice system, and the specific needs of people with disabilities to enable full participation in the legal system
- abuse of children with disabilities in institutional settings including respite services
- lack of access to voting facilities to protect the right to a secret ballot
- gender-based discrimination and violence against women with disabilities
- migration issues, such as the exclusion of the *Migration Act 1958* (Cwlth) from the *Disability Discrimination Act*.

## Proposed solutions

Thirty-one per cent of submissions contended that action is required to ensure greater protection of rights, including a comprehensive legislative and policy review of Commonwealth and state and territory legislation and policies to remove conflicts with the *UN Convention on the Rights of Persons with Disabilities*. One submission noted that the Canadian Supreme Court had developed an analytical tool to test whether laws, policies, programs and standards unlawfully discriminated against people with disabilities. A number of submissions strongly argued that the powers of the Human Rights Commissioner should be extended to investigate cases without the need for an individual complainant, or that advocacy groups should have the right to bring cases on behalf of a group of individuals.

Other suggestions included:

- creating a complaints authority and compliance certification
- providing free legal representation to people with disabilities
- increasing the number of, and funding for, advocacy services for people with disabilities in urban, regional and rural areas, and greater promotion of these services
- enlisting advocates as intermediaries to ensure person-centred processes and models are effective and include measurement of appropriate outcomes
- providing leadership training and capacity building for people with disabilities.

## 2.3 'BROKE AND BROKEN'— THE STRUGGLES OF THE SERVICE SYSTEM

### 2.3.1 LACK OF SERVICES AND SUPPORT



T is 40 years old and has been receiving the Disability Support Pension since he was 18 years old. He went to a regular school but felt he never really fitted in.

T has lived all of his life with his mother who is now 80-years-old. T's mother is suffering from early dementia and this is resulting in friction between T and his mother.

T has been attending a centre for intellectual and development disability. A doctor from the centre reported that a recent WAIS 111 [assessment] showed that T had a full scale of IQ of 72 but his subscales show considerable variation with impaired function in picture arrangement and completion, similarities and coding and relative decrease in his comprehension.

The doctor says T has an inadequate skill base for activities of daily living such as shopping, cooking, tying his shoe laces and self-care, as well as problem-solving and decision-making. He also states he has an anxiety disorder.

T's situation at home with his mother is very unsatisfactory resulting in T having violent verbal outbursts and he fears for his mother's safety because he gets so angry he has trouble controlling himself.

The doctor believes that if T does not get support to move from his mother's home, a more acute situation will arise requiring much more extensive support.

To access disability support services three diagnostic criteria must be met in order to verify a diagnosis of intellectual disability, including IQ assessed as being below 70; limitations in adaptive functioning; and onset before 18-years-old.

The disability support service in T's area argued that as T went to a regular school, as he has been employed as a cleaner with the support of an employment service, and as he has a driver's licence and an IQ of over 70, he does not qualify for support under the service's criteria.

Such eligibility requirements exclude people with IQs higher than 70 who have an impaired function or skill base for daily living (e.g. shopping, cooking, etc.). This population group are overrepresented in the criminal justice system both as victims and offenders.

Disability services are specialist services targeted at people with disabilities, and their families, friends and carers. They can be distinguished from services that are available to the general public, which may or may not be accessible to people with disabilities (also known as 'mainstream', 'generic' or 'universal' services).

Disability services are intended to provide people with disabilities with the assistance they need to participate fully in daily and community life. More than half of the submissions received during the consultation process (56 per cent) said aspects of disability services and programs acted as a barrier to, rather than a facilitator of, their participation. The disability service system was characterised as irretrievably broken and broke, chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need. As a result many felt more time was spent rationing services than delivering them.

Services were characterised as unavailable or unaffordable or of such poor quality as to be of little benefit. Many submissions said that there is little or no choice in services provided, particularly in regional or remote areas. Submissions and participants at community consultations said that the system is characterised by a 'one-size-fits-all' approach in which there is very little choice or flexibility. Programs and services are built around organisational and system needs rather than the needs of clients. As one submission noted,

“ The focus of the strategy needs to be on the individual with the disability with the aim of optimising their quality of life, not creating structures and barriers between levels of government, artificial eligibility criteria or categorising people based on a 'one-size-fits-all' model.

Another submission argued that the one-size-fits-all approach fails to meet the specific needs of individual clients.

“ Teens with intellectual disabilities have particular difficulty accessing [sport and recreation] activities because [they sometimes] need a support person ... Councils often concern themselves with physical access rather than the other supports needed.

Many people with disabilities and their families, friends and carers described their lives as a constant struggle for resources and support. Some said that they were exhausted and worn out with constant battles, haunted by an ever-present fear that even a limited service would be withdrawn.



It is not unusual for people to be left to sleep in their wheelchairs through lack of care hours to get them to bed, or for them to be left without a meal as there is no-one who can prepare it for them.

Many submissions expressed frustration with the bureaucratic nature of service provision. They describe the system as difficult to navigate, excruciatingly slow and unresponsive. Endless assessments and endless forms seem to lead only to a frustratingly inadequate service. The layers of bureaucracy and red tape not only make locating and accessing support difficult, but appear to bleed the system of much-needed resources. As one exasperated parent commented,



They seem to spend more money on case managers than actual therapists.

People with disabilities and their families, friends and carers expressed frustration that, despite the millions allocated by the Commonwealth and state and territory governments, very little seems to trickle down to those who need it the most.



There is a lot of waste and duplication of money, processes and procedures. Why can't they talk with strategic policy makers on the same issues? HACC [the Home and Community Care program] is a federal and state program and local government throws in a few dollars. This delivers on average two hours of services a week. This requires massive infrastructure for people to stay at home for two hours a week for \$12,500.

Services are often so limited that individuals report going to extraordinary lengths to meet eligibility criteria and receive support. This process often leaves them feeling demeaned and humiliated. Parents also expressed frustration at consistently being told to be positive and have high expectations—while at the same time being forced to paint the worst possible picture of their child and their needs in order to access support.

The story of 'T' above also highlights the consequences of severe rationing in the system. With the level of unmet demand already high, many people find themselves 'defined out' of services despite a very real need for assistance. Rationing has created a 'shadow army' of individuals who exist on the margins and who cannot meet strict eligibility criteria for support despite real and pressing needs.

A number of submissions also noted the lack of portability of funding and the resulting difficulties for people with disabilities and their families, friends and carers attempting to move across jurisdictions. One submission described how the rules affected a family member.

“ Another problem with state funding is that a person with a disability can't move from one state to another without experiencing great difficulties. Our son would like to move north but because he is funded by another state this is almost impossible. We approached the authorities and were told that he could apply but would not be considered until he actually lived in the specific state. Even though his funding would be transferred across to his new state, it only lasts one year and then reassessment would occur, leaving us wondering what that would lead to, all in all it is far too difficult and risky for him to move.

Many submissions praised the commitment of staff to their clients, and the dedication with which they carry out their work. They noted that staff often share their frustration with the system. They recognised that many in the service system feel constrained by circumstance, having inherited a highly managed, highly rationed, impoverished system in which the pace of change is frustratingly slow.

Importantly, many argued that the service system is so fundamentally flawed that it is beyond mere bandaid solutions. These submissions maintained that both fundamental systemic reform and greater resourcing are needed to achieve lasting change. They argued for a move away from a welfare model of service provision to a person-centred approach that sees services not as charity but as a social investment in realising the potential of people with disabilities.

“ We can put men on the moon, we can go to war but we cannot fulfil basic needs enabling our disabled community to live with human dignity.

### Proposed solutions

Given the complexity of the service system and its bureaucratic nature, it is not surprising that many proposals focused on improving and simplifying the system (39 per cent). A number of suggestions were made to improve accessibility and reduce red tape and waiting times. There was support for the creation of 'one-stop shops' providing information, advice and referrals.

But it was also clear that many regard the disability service system as irretrievably broken. Merely increasing funding to meet unmet need was, while welcome, seen as insufficient. A fundamental change is required to create a system that truly places people with disabilities and their families, friends and carers at the centre and looks for



creative, innovative solutions to meet their needs. Despite the fact that the rhetoric of ‘person-centred planning’ has become commonplace, many people felt that in practice very little has really changed. Submissions and participants at consultations called for greater availability of individualised funding and services that meet individual needs rather than organisation and system needs. As one submission noted,

“ Overwhelmingly people with disabilities and families say that they want to directly receive government funding so they can purchase their own services. This will provide people with greater control over supports, give them more flexibility, and would contribute to improved quality of service. Overall, this would allow people with disabilities to have wider choice and live with greater dignity.

Another argued,

“ As a carer I need our family’s individuality recognised. One way of doing this is through a flexible funding package enabling us to access mainstream community based activity programs around an interest of our son (and specialist programs when needed).

One respondent, the recipient of an individualised support package, commented on its benefits.

“ For the last 11 years I have been receiving a support and choice package through government funding. Receiving this has enabled me to live independently and continue working. For a number of years I had discussions with the State Government department about managing my own package as I was already doing this informally. In 2008 I was approached by the Department of Human Services to apply to become part of a two year trial of managing my own package. My application was accepted and my involvement in this trial began in February 2009.

Managing my own package has given me the flexibility to alter the assistance I need as my circumstances change. I have also found it to be quite empowering to know I am able to buy services from other agencies when, and if, the need arises. I am extremely conscious of creating a life for myself so that I am not reliant on family and friends. I want to keep them just as that — family and friends — not as carers.

The respondent strongly supported making individualised funding more broadly available. She noted that it would not only allow people with disabilities more control over the services they purchased but would allow them greater choice in where they lived.

A number of submissions also argued that beyond individualised funding, the creation of an external accreditation system and regular monitoring of service standards would help to improve the quality of services and support.

### **2.3.2 WORKFORCE ISSUES**

One clear source of frustration for people with disabilities and their families, friends and carers was the often poor quality of staff in the disability services sector. Submissions argued that many staff are poorly trained and resourced, lack understanding or sensitivity to disability issues and, as a result, offer inadequate or poor-quality care. In some cases inadequate care extended to negligence. Frustration was not limited to disability-specific services but extended to people employed in disability positions in mainstream organisations. Disturbingly, more than 22 per cent of submissions reported that difficulties with staffing represents a significant problem in their lives.

Many submissions noted that the combination of low pay, lack of training and poor working conditions makes it difficult for the sector to attract and retain qualified and quality staff. As a result the system is chronically understaffed, placing additional pressure on already stretched staff. Lack of availability of trained staff is a particular problem in regional and remote areas of Australia. One submission highlighted the difficulties with some paid carers.

“ How do I find an honest, willing carer who will be willing to work for a low wage? You find lazy, dishonest carers everywhere! They take money and cigarettes. One carer I had left leaving me thousands in debt. This man brought his daughter to my home and expected me to feed her. He stole toilet paper, then he just packed up one night and left. They've got you over a barrel because you're at their mercy, and they know it! Finding good carers is very difficult.

A number of submissions also noted that the difficulties in recruiting and retaining qualified staff extends to disability positions in mainstream services. A significant number of submissions argued for improved training in both the health and education sectors in particular to ensure the needs of people with disabilities and their families are appropriately met.

“ I meet parents who are eternally frustrated and upset by the barriers that their child faces such as their teacher is not trained in how to educate their child who is non verbal or has never worked with a child with a disability.

A consultation participant noted,



A lot of deaf people have specific needs and they need to have the most appropriate deaf professional as well ... I don't want hearing people talking with me or talking about my deaf needs with me. I think it's really important that I have deaf counselling services ... We need to train and educate people in that area.

### Proposed solutions

Historically, care work has been devalued. As a number of submissions noted, any reform to the sector must therefore begin with recognition of its importance. It must begin with recognition that these services and supports are essential to a basic standard of living and meaningful participation in community life for people with disabilities and their families, friends and carers. Greater attention to workforce development is essential if the needs of people with disabilities and their families, friends and carers are to be met. Any reforms to the area must focus on the creation and retention of a skilled workforce that is able to provide high-quality support.

While a range of strategies were proposed, most submissions agreed that any reforms must incorporate the following features:

- increased pay rates
- improved conditions
- improved education and training
- development of clear education and career pathways.

### 2.3.3 LACK OF AIDS, EQUIPMENT AND ASSISTIVE TECHNOLOGIES



S is a 45-year-old woman who is blind, and who lives in regional Australia. She is employed, and plays an active role in her local community. S has a university degree in political science, and is a regular contributor to radio current affairs discussion programs.

Despite having a detailed knowledge of Australia's electoral system and being a keen participant in civic life, S had never been able to cast her own vote until the 2007 federal elections.

She relied on family, friends, or electoral officials to complete her ballot paper. She thus could not cast a secret ballot, and had no way of verifying that her intentions were indicated correctly on the ballot paper. She often votes 'below the line' as she has clear ideas about which candidates she wishes to support, and this lack of verification has always been a significant concern for her.

In the 2007 federal elections, S was able to participate in the trial of accessible electronic voting. She had to travel 200 km to attend a polling station where the system had been set up, but although this caused her quite a deal of inconvenience, she undertook the six-hour journey so that she could vote independently for the first time in her life. She was able to use the system with its speech output (delivered through headphones) and was pleased that the system had the facility for her to review her ballot paper so that she could confirm her voting preferences. S reports that she felt empowered and affirmed by the experience of casting her own vote, and is lobbying for the system to be introduced in all Australian elections.

Elsewhere in the world, people with disabilities have a legislated right to the aids, equipment and technology they require for daily living. No such right exists in Australia. As a number of submissions made clear, people with disabilities and their families, friends and carers find it incredibly difficult and sometimes impossible to access the aids and equipment essential to daily functioning. Their ability to lead an independent life is severely compromised as a result. The provision of aids and equipment is intended to ensure that people with disabilities have the required resources to participate fully in community life. Sadly, more than 20 per cent of submissions reported that a lack of aids and equipment acted as a barrier to their participation in the community. As one submission noted,

“ “ There is much talk of community involvement and participation, but when individuals don't have access to the necessary mobility and communication tools to partake, then it is not possible.

People with disabilities and their families, friends and carers reported difficulties with eligibility for aids and equipment as well as long waiting times for assistance.

“ “ A child we will call S is 8-years-old and lives in a small rural community with her mother and siblings. S has cerebral palsy and uses a wheelchair permanently. She is unable to use verbal communication and uses a speech activated computer and has a manual wheelchair and attends public school.

Her mother has applied for and been waiting several years for an electric wheelchair for S, which would enable her to be more active at school with her friends and be more independent than she is. This would also free up her mother from having to push S everywhere as she is unable to use a manual wheelchair herself. S has a highly active mind and is very intelligent and without the use of an electric wheelchair and an up-to-date communications system she will flounder and the opportunity for a bright child to advance will be lost.

In another case, a family required a hoist to lift their adult son in and out of bed. But they were unable to apply for funding until an occupational therapist conducted an assessment. The waiting time for an assessment was 18 months.

Difficulties with eligibility were particularly experienced by those who required wheelchairs or hearing aids. A number of submissions noted that government subsidies for hearing aids are not available for working people over the age of 21.

Lack of availability or lengthy waiting periods forces people with disabilities and their families into purchasing aids and equipment themselves, often at considerable expense. When beyond the budget, people with disabilities are forced to go without for extended periods of time. Either way, the quality of life of people with disabilities and their families is significantly compromised.

Submissions also discussed difficulties with fitting, adjustments, modifications and repairs. Some noted that even when available, equipment is not always suitable.

“ “ Why does my daughter have a communication device that talks in a male American computerised voice? Why can't she have a communication device that has a voice of a young Australian girl?

## Proposed solutions

There are currently multiple aids and equipment schemes operating across the country. Many submissions argued that a nationally coordinated and funded equipment scheme would eliminate existing inequities and ensure portability across jurisdictions. Some suggested that equipment could be made available through Medicare.

Others suggested improving tax concessions and rebates for those purchasing their own equipment. And some suggested broadening the existing communications allowance into a utilities allowance.

Submissions also argued that each sector should have appropriate resources to ensure staff have up-to-date knowledge of assistive technologies and the means to investigate developments in the interface between mainstream and assistive technologies. Others focused on ways to facilitate further research and development. A small number noted, however, that there is a tendency to rely on high technology when in fact for many people, particularly those with a communication disability, low-technology solutions are useful and appropriate but often overlooked.

### 2.3.4 LACK OF HOUSING OPTIONS



Many people with intellectual disability live in group homes, and while some would argue that this is an improvement on the previous large institutional arrangements, these environments still congregate and segregate people in a way which inhibits community inclusion. Further, people living in these arrangements have very little choice about who they live with, whereas non-disabled community members who choose to share accommodation with others generally do have this choice ...

It is reasonable to argue that very few people living in group homes would choose to live in such a setting if they had a realistic choice. It is a compromise brought about by necessity, as they do not have enough support through funding for paid support, even augmented by their family and informal support networks, to live in their own home... The concept of community living for people with intellectual disability is a much richer concept than a mere physical presence in a community setting, which by itself does not guarantee community integration and inclusion. As support workers often work alone, there remains significant risk of abuse and neglect.

“ A woman with a physical disability was forced to move into a group home with two men with autism when her family was no longer able to support her. The woman feared for her safety as she had no way of defending herself when she was hit by one of the men...

“ A mother complained that her son was being repeatedly sexually assaulted by a resident of his group home. The service was not able to move the other man to alternate accommodation because none existed.

Few things are more fundamental than having somewhere to live. Having little or no choice in where one lives has a profound impact on physical and mental health, and the ability to participate in employment and community activities. Yet this is precisely the experience of many people with disabilities. More than 32 per cent of submissions identified difficulties with housing and accommodation. Concern included a lack of support for people in private dwellings (owned or rented) as well as those in a range of publicly funded models of accommodation such as group homes, cluster housing or large residential centres (congregate institutions).

Few Australians without a disability can imagine what it would be like to have no say in where they live or who they live with. The freedom to choose where and with whom one lives is a fundamental freedom, but it is one few people with disabilities are able to exercise. Many people with disabilities want to live independently in the community but are unable to access the support they need to do so. Many parents also reported profound frustration that despite their desire to see their adult son or daughter move out of the family home, there was simply nowhere for their child to go.

Some estimates suggest that only a very small percentage of people with a severe or profound disability receive any form of government-funded accommodation support. The shortage of accommodation has meant that even those on emergency waiting lists can wait years for assistance. Lack of alternatives also means that those who are currently in unsuitable arrangements have very little chance of moving. For some this results in a severely compromised quality of life. For a small number it leads to continued victimisation and abuse.

Submissions were both passionate and desperate in their calls for increased funding of accommodation options.

“ Our daughter is 18. She has a severe intellectual disability and is fully dependent on us for all her needs. [She] displays challenging behaviours, which makes daily activities within the family very demanding. [She] presently attends school and accesses respite two nights per week during school weeks. This arrangement will cease at the end of 2008 as [she] will be leaving the educational system. We understand there will

be no supported accommodation made available to us in the future. Our greatest concern for the future is that due to our daughter's high support needs we will be unable to continue in our present work situation.

It would appear that the government thinks that once disabled children turn 18, they all of a sudden find independence and need less support. Well, let me tell you they are still the same people they were when they were children, they need care 24/7, they won't get a job and they cannot look after themselves until Mum and Dad get home from work. This will not change for the rest of their lives, this is reality. We care for our children and want to continue to do so, but cannot do it without support from the government. Do we have to hit crisis point before you will listen?

The desperation of ageing parents haunted by the thought of what will happen to their children when they are no longer able to provide a high level of care and support was a sad recurring theme in submissions. The crisis in accommodation means that few are able to plan effectively, and transitions out of the family home are therefore often traumatic rather than seamless.

“ I didn't want to be a carer in my older age. I originally was a teacher. I found it very hard. No-one told me anything about how to get help and I was looking after her [my daughter] 24-hours-a-day by myself for quite a while. I took her to the hospital (for rehabilitation). By February the doctor called me up, only wanting to tell me this wasn't the place for her. And then I said, 'Well, I'm leaving her here until I either get rehabilitation or help.' I tearfully went home and my daughter was very upset and when I got home the social worker rang me and said, 'You can't leave your daughter here.' I said, 'Well, I am until you get one or the other or both.' She said, 'We will send her to a nursing home.' I said, 'You can't because I am her guardian.' She said, 'We will get the government to take the guardianship off you.' So that's how I was treated as a carer.

“ Some of the carers are in their late 80s or 90s and have terminal illness. Many or almost all of the carers do not have other family members to care for their son or daughter which means they need to be placed in supported accommodation... [P]lacements are governed by the Department who operate a panel for eligibility. This is decided on a priority basis. This process usually means



persons have little choice in accommodation [when] their parents are critically ill or have [died]. All of the carers would like to be part of the process of transitioning their son or daughter in care. I have witnessed intense worry for the carers and the care recipient waiting for an appropriate placement. Many will not live to see this. I see this as a priority as there is currently no choice for a person with a disability and entry into supported accommodation is largely crisis driven, causing carers and care recipients undue suffering.

When accommodation cannot be found sometimes extended family members are pressed into service.

“ A middle-aged man was concerned about his elderly sick mother who was looking after his three siblings who have an intellectual disability. The man had pledged that when his mother died, two of the siblings would come to live with his family but it would be difficult to support his older brother whose needs were more significant and complex. The man tried to organise for his brother to move into government funded accommodation but was told he could not do so because the mother had not tried all forms of respite care as a way of keeping her son at home.

Another commented,

“ Governments rely on most parents never being able to bring themselves to abandon their children. Deep parental love and a sense of duty are being deliberately exploited solely in order to save money, which in a country as wealthy as Australia, is profoundly shocking. But even the most devoted and self sacrificing of parents can't keep on caring if they're dead.

Sadly a number of submissions noted that sometimes the only way to access out-of-home accommodation is abandonment to state care.

Respondents expressed frustration not only with the lack of funding for accommodation but also the lack of appropriate or suitable models. Alternatives to group homes are few and far between and for some lead to a restricted lifestyle and poor quality of life with limited opportunities for independence.

One family expressed frustration at the treatment of their 31-year-old son who lived in a community residential unit. Despite his age, the young man was forced to go to bed at 8.30pm and was punished if he got up 'too early'. He was forced to travel in a van with a cage even though he was a regular passenger in the cars of family and friends.

For this family, this did not appear to be ‘independent living’. For young people who require a high level of support and care, there appear to be few alternatives to life in a nursing home. Despite recent commitments to the development of alternative models, too few people are able to access age-appropriate care that meets their individual needs.

And as a small number of submissions noted, it is also important to remember that despite more than 20 years of deinstitutionalisation, a significant number of people with an intellectual disability still find themselves ‘warehoused’ in large congregate institutions. As these submissions noted, many people are unaware of the experiences of this vulnerable group.

### Proposed solutions

Most submissions that addressed housing and accommodation highlighted one main issue—lack of choice. Proposed solutions focused on the development and resourcing of alternative models. An injection of funds to increase the availability of accommodation options to relieve the crisis in unmet need is clearly required. But beyond increased funding, most submissions in this area called for more creative thinking and the development of models that are more responsive to individual need and lifestyle. Many hoped the greater availability of individual support packages would allow some to purchase services to enable them to live a more independent life in their own home.

Proposals included:

- developing lower cost, higher empowerment supported accommodation models for people with an intellectual disability
- introducing accommodation and support services run by and for Aboriginal and Torres Strait Islander people with disabilities
- developing outcome-based key performance indicators and enforceable standards for all forms of accommodation as part of an accreditation process
- increasing the availability of public housing stock for people with disabilities.

## 2.3.5 THE IMPORTANCE OF HEALTH AND WELLBEING



Born with motor neurone disease, D’s mother did everything for her for her whole life. Although she was capable, she had never even washed her own hair until after her mother died when she was 32.

After the initial shock, and being nearly forced to live in a nursing home, five years later D was living independently on her own. She had started a social group for young people in nursing homes.

We were about to have a housewarming party to celebrate this massive achievement of living on her own when D became ill. No one thought that she should have yearly health checks and she developed kidney stones. With her disability she couldn't feel anything from her stomach down and so didn't get the warning signs that people who can feel do.

One night on her own she rang the after hours care to tell them she needed help and would they send someone to help take her to hospital. The After Hours Disability Service determined over the phone that she was not sick enough to warrant a visit. D then had to ring the ambulance herself, on her own she went to hospital distressed.

She was sent to intensive care and put into a medically induced coma. Five months later she passed away. She never went back to her home to live.

She was let down on so many levels.

People with disabilities require the same access to health care as all other Australians, yet experience considerable difficulties receiving appropriate care. More than 29 per cent of submissions identified problems with health care. At consultations across the country many people passionately argued that the gaps are so considerable and care so compromised that people with disabilities experience not only a poor quality of life, but also threats to their very lives. These participants strongly argued that poor health care is contributing to a reduced life expectancy for people with disabilities.

Submissions argued that many in the health and allied health sector receive very little training regarding disability and therefore have little understanding of the health needs of people with disabilities. More disturbingly, some argued that myths and misconceptions regarding disability are affecting clinical decisions and compromising quality of care.



There's a lot of 'she's in a wheelchair, take an aspirin and go home'.

Health professionals who were considered poorly trained to work with people with disabilities included doctors, nurses, specialists, pharmacists, community health care workers, and allied health professionals such as audiologists.



They need clear signage, awareness and education for people in the hospital system for deaf people, especially when you are sick and unable to convey your needs.

Submissions argued that despite their training, health professionals hold the same beliefs and misconceptions about disability as the rest of the community. Ironically, because of their training they are often less likely to acknowledge this. As one respondent noted,

“ Those GPs who have myths about disability and sexuality may refuse to give women with a disability a pap smear.

One submission noted that there appears to be little awareness of the mental health needs of people with intellectual disabilities, particularly as they age. This was seen as a pressing issue for future planning.

A number of submissions also noted the lack of availability of early intervention, particularly for children with disabilities. These submissions argued that while early intervention is essential to ensuring children with disabilities grow up to reach their full potential, most children receive only a few hours of support a week. With such limited availability, the burden falls on parents to source and pay for other kinds of support or carry out the work themselves. While parents clearly expected to be active participants in meeting the additional needs of their children, there was considerable stress, resentment and anger at the perceived transfer of responsibility of early intervention to parents. And as these submissions noted, investment in early intervention not only ensures optimal outcomes but reduces costs associated with support over a lifetime.

“ Ideally, early intervention should be a one-stop-shop for parents and carers seeking support in the early years of a child’s life, this period typically being one of the most stressful in the journey of a family with a disabled member.

### Proposed solutions

Most proposed solutions focused on the need for greater funding of health care for people with disabilities to ensure all their health needs are met, including expansion of the health care card system to improve access and affordability and increased subsidies for essential medications. Most submissions also advocated for improved training of health and allied health professionals.

Submissions also called for greater funding of early intervention for children with disabilities, and more extensive research into effective methods and practices.

## 2.3.6 POVERTY AND THE COST OF LIVING WITH DISABILITIES



R is 51. He is blind, and also has a severe hearing impairment that is becoming more severe with time. R is entitled to receive free hearing aids through Australian Hearing Services. However, because of the lengthy waiting list for appointments, it can take months for him to have adjustments made as his hearing deteriorates. Because he wants to live independently and be as active as possible, including maintaining employment, R has decided he has no option but to use the services of a private audiologist and purchase hearing aids in the marketplace. This amounts to around \$9,000 every four to five years.

R is a parent, and has primary care of his teenage daughter. He needs to live close to his daughter's school, but this means that he cannot use public transport to go to work each day. So he spends about \$400 per week in taxi fares, even after the use of a transport subsidy voucher book that pays \$30 per trip. As a recipient of the Disability Support Pension (Blind), R receives a Mobility Allowance to help cover transport costs. However, the Mobility Allowance is only \$37 per week—less than the cost of one of his daily taxi trips.

R also has to spend money on computer equipment and adaptive technology for his private use, as well as on home maintenance and the usual household expenses. There is little left over for non-discretionary expenses such as leisure and entertainment, and R is not in a position to save for the future. If R chose not to work, he would probably not be significantly worse off financially, and he would be more likely to be able to use his entitlement of free hearing aids through Australian Hearing Services. If he could claim his work-related transport expenses as tax deductions, and if there were a scheme for subsidising the purchase of assistive technology for private use, R's financial position would be similar to that of a person without a disability who worked in a similar job.

Australian Bureau of Statistics data have long demonstrated that people with disabilities are less likely to be employed, more likely to be dependent on income support and more likely to live below the poverty line. These stark statistics were heartbreakingly illustrated by a large number of submissions that detailed the grim reality of life on the Disability Support Pension. Resented by some in the community for their reliance on the pension, yet unable to access the support required to move off it, many people with disabilities find themselves trapped in a poverty cycle of high cost and low income. More than 37 per cent of submissions highlighted the difficulties involved in juggling the high cost of living with disabilities and the low level of income support available.

As one submission noted,

“ The costs of mobility aids (like wheelchairs or scooters), communication aids, specifically designed therapies, paid carers and supports, home renovations, etc are all very costly to ordinary people living on pensions or benefits.

The extraordinary gap between the level of income support and the cost of disability was seen as restricting the ability of people with disabilities both to live independently and to enjoy a decent standard of living.

“ Disability support recipients live lives of fear and desperation. Sooner or later every disability support recipient I know has confessed to the concern they feel over the ‘what if’ factor—what if government stops paying social security/disability support?

Gaps in the service system mean that many people with disabilities and their families, friends and carers are forced to meet the cost of essential services and support themselves. As many noted, this leaves little discretionary income to meet basic living costs.

“ E cannot travel in a normal family sedan. E must travel in her wheelchair to preserve her comfort and safety because it is not possible for her to be safely transferred to or secured into a regular car seat. This requires a van customised to fit E’s wheelchair as the only means to allow her to participate in normal community life ... The provision of specialised transport is a significant cost to carers. The cost should attract Government support.

As a result, families caring for a member with a disability also find themselves caught in the poverty trap. Many said they were forced to fund private services that were unavailable elsewhere, which put a significant dent in the family budget.

Many submissions also noted the inflexibility of the application process and eligibility criteria of the Disability Support Pension, which acts as a disincentive to full employment. These submissions reported that the transition from the Disability Support Pension to paid employment often incurs significant financial costs, including transport and increased fees for support services. Such costs often lead to decreased income, and therefore act as a disincentive to seeking employment. These submissions argued that the rules and policies around the payment of the pension require review.

### Proposed solutions

Most respondents welcomed the Harmer Pension Review and the Henry Review of Taxation (Inquiry into Australia’s Future Tax System). Many suggested that the review of the Disability Support Pension should be extended to include other allowances,

including the Carer Payment and Carer Allowance. Some suggested that any proposed increase to the pension and allowance system should be based on modelling of the true costs of disability and caring (including indirect costs such as foregone earnings, superannuation contributions and interest). One submission, for example, suggested that the Disability Support Pension could be tiered to reflect costs associated with disability. Others argued that the Disability Support Pension should be scrapped entirely in favour of a modular Disability Allowance. This allowance would be tax-exempt, not means-tested, and based on an assessment of the nature and costs associated with an individual's disability.

Existing allowances were well supported, with suggested changes to current age limits. An enhanced Communications Allowance to cover the additional costs of using information and communications technology products and services (such as mobile phones and broadband) was also proposed, as well as a disability study allowance or 'Dis-study', similar to the current Abstudy allowance for Aboriginal and Torres Strait Islander people. The creation of a low-interest loan scheme for disability-related costs was also suggested.

A number of submissions suggested that the high costs associated with disability could also be addressed by changes to the tax system. These submissions argued that people with disabilities should be entitled to rebates or deductions for associated costs.

### **2.3.7 THE NEED FOR A LIFETIME CARE AND SUPPORT SCHEME**

The chronic underfunding that has characterised the disability service sector for decades has had many consequences. The extraordinary level of unmet need has forced many people with disabilities and their families to purchase services and support privately, contributing to the high cost of living with a disability and trapping many people and their families in a desperate cycle of poverty. It has also resulted in a demand-management approach to service delivery, with greater attention paid to rationing services than meeting individual need. Resource constraints also contribute to a one-size-fits-all approach. Most importantly, the system clearly fails to ensure people with disabilities have the support they require to live as independent a life as possible, and enjoy a quality of life others in the community take for granted. Many submissions argued that the service system is so fundamentally flawed as to be beyond bandaid solutions, requiring a complete overhaul to deliver lasting change. And many saw the creation of a lifetime care and support scheme (sometimes known as a national disability insurance scheme) as the paradigm change required.

Despite recent commitments to an increase in resources, submissions argued that the system is clearly unable to meet current need and has limited capacity to meet anticipated increases in demand. They also spoke of a pressing need to address inequities in the system, which result in people with disabilities receiving different

levels of support depending on how their disability was acquired. According to these submissions, the only answer is to create a model of funding in which resources are available irrespective of changes to the economic climate, government budgetary cycles or variability in political will. While details varied, these submissions argued that a lifetime care and support scheme would remove existing inequities and provide the resources needed to ensure people with disabilities are able to reach their full potential and live as independently as possible. As one submission noted,

“ National compulsory superannuation and health insurance (Medicare) are already accepted as key pillars of Australian public policy. Many of the principles underlying government decision making on superannuation and health insurance also apply to the disability area.

While another argued,

“ A commitment from all governments to the provision of essential services for people no matter how they acquired their disability is essential. It is only with this basic commitment ... that we can make any substantial progress.

A number of submissions argued that the introduction of a national scheme and the resulting pressure to reduce long-term costs would produce system efficiencies and a greater devotion of resources to early intervention and to those services and supports that maximise independence and potential. It would also allow for a lifetime approach to care and support and facilitate improved long-term planning. In short, it would provide a driver for the kinds of reforms to services that people with disabilities and their families, friends and carers say they would desperately like to see.

Details of the proposed schemes varied and a range of models were suggested.

They included:

- a universal national compensation scheme for people who have a permanent 'severe and profound' impairment
- a national disability insurance scheme comparable to the Medicare system to fund care and support systems
- a national insurance scheme, with no age barrier, for people who are catastrophically injured
- a national catastrophic insurance scheme to support people with a newly acquired disability
- a national insurance scheme for people with acquired disabilities (through an accident).



## 2.4 'CAN'T GET A JOB' — THE EMPLOYMENT EXPERIENCE OF PEOPLE WITH DISABILITIES



B is a 45-year-old woman. Several years ago she was diagnosed with Type 2 diabetes, and this has now led to the loss of most of her vision. She lost her job last year after her employer refused to provide workplace adjustments or give her time off to learn how to use assistive technology. She is now finding it harder and harder to cope, and is stressed and anxious most of the time because she can't get accurate and consistent information about the social security benefits she is eligible to receive as an unemployed person. Most of the printed information is inaccessible to her, and she can't fill in the forms independently.

Meaningful employment is essential not only to an individual's economic security but also their physical and mental health, personal wellbeing and sense of identity. Unfortunately, too few people with disabilities appear able to access meaningful employment. More than 33 per cent of submissions identified difficulties with employment, ranging from active and open employer discrimination to misconceptions and misunderstandings about the needs of people with disabilities. What was clear from the submissions was that people with disabilities want to work. What most lack is not ability but opportunity.

Submissions detailed difficulties in seeking, obtaining and retaining employment. By far the biggest barrier identified was employer attitudes. These ranged from entrenched discrimination to misconceptions about the adjustments required for some people with disabilities. Discrimination occurred in those cases where otherwise qualified candidates for jobs were screened out or overlooked simply because of their disability. As one submission noted,



Some employers and recruitment agencies are using medical tests to 'screen out' candidates with disabilities which are irrelevant to their ability to perform the job. This occurs particularly when the tests are used in a generic rather than job specific manner.

Others reported that discrimination and negative attitudes had a more subtle impact on their experience of employment.



I definitely made the correct decision when diagnosed about five years ago to limit the people and work colleagues who knew of my situation to a small number. Once the full extent of my situation became 'public' to work managers and HR, the barriers began to build. This took the form of well meaning but restrictive measures under the guise of 'duty of care'. Freedom of movement including no longer being allowed to drive a work vehicle meant the loss of a portion of my independence, even though there were no restrictions on my driving outside of work. The psychological impact was that for the first time I started to feel like a disabled person rather than a person with a disability. Believe me, they are two very different feelings.

It was clear from the submissions that there are still widespread misconceptions and stereotypes influencing the attitudes and behaviour of employers, recruiters and government. Such negative attitudes can restrict the ability of people with disabilities to get a job or, if they manage to obtain employment, impact on their ability to do their job effectively. The following comment illustrates the difficulties.



I have had bosses in the past who don't understand that I need an interpreter and they go ahead without one. It really puts me in a difficult situation to try to keep up with what is being said. Usually I end up just sitting there and can't say anything, and don't really follow. It makes me feel embarrassed and angry.

Groups that experience significant social stigma, such as people with a mental illness or an intellectual disability, reported particular difficulties in obtaining and retaining employment.

Submissions noted that the perception of employment as charity also has a negative impact on people with disabilities. The concept of 'giving someone a break' fails to recognise the important economic benefits of ensuring skilled individuals are able to participate fully in the economy. Greater independence also produces long-term benefits by enabling people to become less reliant on government income support.

Submissions also made clear that there is considerable misunderstanding in the community about the cost of workplace adjustments. The need for expensive adjustments is often cited by employers as a reason for not employing more people with disabilities. But the cost is often considerably overestimated. As the following case study illustrates, the benefits of employing a skilled individual far outweigh the often small costs of modification.



An organisation was looking for an administrative officer. One of the requirements of the position was the transcription of lengthy taped material. For a long time the organisation had been unable to find a cost effective method of transcription — the employer commented that it had become a lost art. Through an organisation specialising in assisting people with a disability to find employment, the employer located a young woman with a vision impairment who had the right set of skills. The only workplace modification required was the installation of a computer program to verbalise word documents and a dual headset to enable her to listen to the tapes. Productivity in the area increased considerably after the young woman joined the administrative team. The employer was delighted with the change and commented that ‘by investing in the right person you will reap the benefits’.

As a number of submissions noted, workplace modifications are not always necessary. As the following case study suggests, what is sometimes required is additional support or a more flexible approach to working hours or leave. Such an approach benefits all employees in the organisation.



Injuries sustained in a serious car accident left one woman unable to continue in her current occupation. Searching for alternative employment, she applied for job after job, but was never offered an interview. Determined to be fair and honest, she disclosed her medical history in her applications. She believes her decision to be frank was behind her constant rejections. She finally responded to a position within the Australian Public Service and was successful. The flexible working arrangements offered to all employees allowed her to keep her medical appointments without requiring additional leave. After constant rejection, she was delighted to find a workplace committed to being more inclusive.

Occupational health and safety requirements are also sometimes used as an excuse for restricting function or refusing employment. But once again submissions noted that there is often considerable confusion about the impact of requirements on people with disabilities.

Lack of employment has resulted in high levels of unemployment and underemployment among people with disabilities compared to the rest of the Australian population—Australian Bureau of Statistics data demonstrate that labour

force participation for people with disabilities is 53 per cent, compared to 81 per cent for people without disabilities.<sup>3</sup> These figures do not, however, capture the extent and impact of underemployment. As one submission noted,



A recent study by Vision Australia found that 63 per cent of people who are blind or vision impaired are underemployed or unemployed.

Many people with disabilities and their families are therefore forced to rely on government assistance and find themselves trapped in a poverty cycle of low income and high costs. A number of submissions said that the inflexibility of the Disability Support Pension acts as a disincentive to employment and recommended a review. The loss of health care benefits was seen as a particular difficulty.

### Proposed solutions

For many respondents the answer seemed clear—more jobs. The fundamental importance of a secure source of income and the social benefits of employment appeared obvious to many. A number of submissions argued that the government should lead from the front and improve public service participation rates. Many also noted that organisations serving and supporting people with disabilities have a poor record of employing people with disabilities and should take responsibility for demonstrating a commitment to change.

Submissions also made clear the need to address negative employer and recruiter attitudes. Educating employers about disability and ensuring resources are available to assist them were recurring themes. There was, however, a note of caution—while welcoming improved awareness and education, submissions argued that such schemes would only be effective if they led to real behavioural change.

A number of submissions also noted that there is a lack of flexibility to support people with disabilities in seeking and retaining employment—like other disability services, there is a tendency to adopt a one-size-fits-all approach. These submissions recommended the development of a more flexible individualised approach to ensuring people with disabilities obtain the support required. This was seen as particularly important for individuals who require varying levels of support over time.

Other suggestions included:

- setting employment targets in the public service at Commonwealth, state and territory and local government levels
- tracking students with disabilities after completion of school to determine how their funding and level of education translated to training and employment

<sup>3</sup> Australian Bureau of Statistics, 2003, *Disability, Ageing and Carers: summary of findings*, cat. no. 4430.0, ABS, Canberra.

- enabling students and graduates with disabilities to apply for equity-based programs that get people with disabilities into graduate jobs, akin to Indigenous cadetships
- immediately releasing 100–500 jobs to people with disabilities, through pilot programs, apprenticeships and training.

## 2.5 ‘CAN’T GET THERE, CAN’T GET IN, CAN’T GET IT’— NEGOTIATING THE BUILT ENVIRONMENT

### 2.5.1 LACK OF ACCESS TO THE BUILT ENVIRONMENT AND INFORMATION

“ “ We want to contribute to Australian society but we usually find that we can’t access the workplace, can’t access public venues, can’t have a holiday because there is no suitable accommodation.

“ “ There are a number of so-called ‘wheelchair accessible’ toilets on my campus, but there is only one on the entire campus that I can fit in with my motorised scooter.

“ “ Many professional services [such as dentists] are based on secondary levels with stair access only. Many cafes have step entry. My family or carer and I are forced to utilise outdoor street seating which on many occasions is the colder or less desirable alternative. Cinemas and swimming facilities are still often inaccessible. This prevents me from participating in these recreational activities with family and friends.

The impact of people on the environment is an issue currently being given considerable attention. But the impact of the built environment on people is something many rarely consider. For many people with disabilities the built environment acts as a powerful barrier to their full inclusion in the community. It affects their day-to-day functioning in ways few others can appreciate. The inability of people with disabilities to access the facilities that everyone else in the community takes for granted—cafes, public buildings, swimming pools, libraries, sporting facilities and movie theatres—limits their independence and compromises their quality of life. More than 27 per cent of respondents said that lack of access to the environment acts as a barrier to their full participation in the life of the community.

It is hard for people without a disability to imagine the difficulties many people with disabilities encounter as they move around the community. Organising to meet a group of friends for dinner only to discover the restaurant is inaccessible. Being unable to attend a child's end-of-year ballet concert because the venue has no access. Not being able to go to the movies because there are no screens with technology to assist people with a hearing impairment. Playgrounds that contain accessible equipment but that are routinely locked and can only be accessed with a key.

And, as a number of submissions noted, accessibility issues rarely end at the front door. Once inside, many people with disabilities encounter further barriers such as a lack of accessible bathrooms or lifts without Braille signage. Uneven surfaces, reflective surfaces, narrow doorways, and a lack of clear signage all affect the ability of people with disabilities to successfully negotiate the interiors of many buildings.

As these submissions highlighted, there appear to be multiple barriers to change, including a lack of understanding and awareness in the community about access issues and a lack of comprehension of both the economic and social benefits of implementing universal design principles. Many submissions noted that as the Australian population ages the need for accessible buildings, facilities and spaces will only increase. Yet people in the community still tend to regard accessibility as someone else's problem.

But as the following submission illustrates, even when business owners grasp the benefits there are other barriers.



An Adelaide entertainment business recognised that a number of its customers with disabilities were having great difficulty in getting up stairs at the entry and that a ramp was too steep for people using a wheelchair unless they had a lot of help.

The proprietor had a plan made of an accessible entrance and found that this would cost tens of thousands of dollars. He couldn't afford this unless he could expand his revenue. He applied to the local council to develop an outdoor dining area and made a number of adjustments to minimise the impact of noise on the neighbourhood at some extra cost.

The local community was invited to comment on the proposed plan and nearby residents objected to the potential for more noise in the area. The council decided to reject the application because of this and the access plan didn't happen.

The business is profitable and could have made the access changes with a low interest loan from a National Access Infrastructure Fund. The improved access would have increased patronage and profits over time and the loan would have been paid back.

Many submissions noted that a complex web of regulations, policies and processes across all three levels of government determine the accessibility of the environment. The complexity of the area itself acts as a barrier to change. And despite the overall complexity, there are still significant legislative regulatory and policy gaps that allow parts of the built environment to remain inaccessible.

But for people with a sensory impairment or an intellectual disability, access issues go far beyond structural features. For these groups, access to information remains problematic. Information is rarely provided in alternative accessible formats, including plain English. And yet as many submissions argued, information is essential to meaningful participation in a range of activities, as well as essential to understanding and exercising basic rights.

**Proposed solutions**

Proposed solutions focused primarily on the need for greater regulatory and legislative oversight to ensure existing and future infrastructure complies with universal design principles, including public buildings, public spaces, private businesses and private dwellings. The House of Representatives Inquiry into the draft Disability (Access to Premises—Buildings) Standards was well supported. Submissions also argued that more resources should be made available for upgrades, modifications and retrofitting. A number also suggested creating a fund for low-interest loans for businesses and facilities to enable them to become more accessible. Another suggested modifying government procurement practices to ensure all facilities and equipment purchased by government are fully accessible.

“ Make all levels of sustainability—environmental, social and economic—part of the brief of the Built Environment Industry Innovation Council. Encourage integration and universal design principles across government planning stages.

**2.5.2 LACK OF ACCESS TO TRANSPORT**

“ The cost of transport or the lack of availability of transport often means that people with disability cannot access education, employment services or the community. It is a pivotal support service which is often not available which then excludes the person from many or all aspects of their community.

Few things are more fundamental than the ability to get where one needs to go. Without access to transport, participation in such critical activities as education, employment and health care is difficult, if not impossible. Yet this is the situation many

people with disabilities find themselves in. Submissions consistently reported that lack of access to transport significantly curtails the ability of people with disabilities to participate fully in community life—more than 29 per cent of submissions argued that difficulties with transport act as a barrier in their day-to-day lives. And while most agreed some progress has been made, all said that the timetable for change is far too long. As many noted, the *Disability Standards for Accessible Public Transport* (2002) has a 30-year timetable. These same standards stipulate that only 50 per cent of buses have to be accessible by 2012.

For most, the inaccessibility of public transport leaves them reliant on family or friends or on the taxi system. Both compromise their ability to live independently. And while most states operate a taxi voucher scheme, few provide enough assistance to meet day-to-day needs. This leaves people with disabilities and their families with no other option but to meet all additional costs. As one respondent noted,

“ Although many individuals are provided with access to cab vouchers, the limited number of vouchers means that clients must limit travel or alternately have to pay significant transport costs.

Another noted that lack of transport has a significant impact on her university studies.

“ The transport system as it now stands is very stressful. The biggest issue I have is not being allowed to use my tertiary vouchers at any other time other than lectures. It means I have to stay at home struggling with my assignments on my own. I need to be able to move around Uni on other days within the confines of my courses to achieve the best result. I need the support from other students and to be able to bounce ideas off them—to be part of a team. These restrictions cause isolation, low self-esteem and one is made to feel that we are different.

The additional expense of taxis was not the only reported problem. Submissions also detailed difficulties in accessing taxis, with the lack of availability of accessible taxis a particular problem for people with a physical disability. Poorly trained staff and inflexible services were other common complaints.

Many respondents noted that poorly trained staff are also an issue on public transport. Staff refusing to provide access or assistance despite being required to do so is a particular problem. People with disabilities are clearly still at significant risk of discrimination at the hands of individual operators. Participants at consultations also expressed concern over safety issues when using public transport.



The difficulties confronting people with disabilities in accessing transport are clearly compounded in rural and regional areas. There are even fewer alternatives in non-metropolitan areas, which severely curtails the independence of people with disabilities and compromises their quality of life. Ironically, transport is even more critical in these areas to counter social isolation.

A small number of submissions detailed continuing concerns about travel by air. Despite considerable attention to the issue, people with disabilities are still unable to access air travel in the same way as other members of the community. The inability or unwillingness of staff to assist travellers and the requirement to purchase additional tickets for carers are two issues that remain unresolved. The significant costs associated with pursuing a case through the Australian Human Rights Commission against airlines with significant resources at their disposal can act as a deterrent to achieving change through the legal system.

### Proposed solutions

Most of the proposed solutions focused on increasing access and affordability. A number of submissions suggested that the current schedule of change conducted under the *Disability Standards for Accessible Public Transport* is in need of significant review, while others suggested that creating a central authority responsible for overseeing compliance with the *Disability Discrimination Act* would improve accessibility. Others argued for an expansion of the fleet of accessible taxis. Most submissions also noted the need for improved education and training of transport operators, including taxi drivers.



There should be a bonus system for taxi drivers if they do their job well—they are not well paid.

Other suggestions included introducing a nationwide travel concession card and extending the current subsidy cap for people with disabilities living in rural and regional areas.

## 2.6 ‘THE WASTED YEARS’— THE EDUCATION EXPERIENCE OF PEOPLE WITH DISABILITIES



I remember my Year 8 science teacher said she couldn't wear my Microphone because it put holes in her clothes. I couldn't do anything about it ... she was the teacher—I was the student. For the record—I failed Year 8 science—and it had nothing to do with my ability because in Year 9 science, I had a teacher who wore the Mic and I topped the class.



Equal access to educational opportunities is considered a fundamental right, according to the Australian constitution. However, it is clear that when it comes to delivery of such educational opportunities to disabled people, real educational opportunities are hard to come by ... [The] lack of appropriate funding, classroom support and specialised equipment are enormous barriers to educational opportunities.

Education determines more than a child's economic future—it is also critical to a child's social and emotional development, to establishing a sense of identity and sense of place in the world. Education represents an important opportunity to imagine and create an alternative future for individuals—and unfortunately many young people with disabilities appear to be missing out on that chance. More than 29 per cent of submissions said that, far from ensuring young people with disabilities have every opportunity to realise their potential, the education system acts as a barrier to greater achievement and independence in their lives.

As a number of submissions noted, true inclusion is about more than location—it is about achieving the same quality of education. Yet all indicators suggest that for young people with disabilities this has yet to be achieved. Despite education standards drafted under the *Disability Discrimination Act*, the education system continues to fail to respond to the needs of students with disabilities and, as a result, these students continue to lag behind on a range of attainment indicators. As a number of submissions argued, these results are not a reflection of a lack of ability of students but of the failure of the system to meet their individual needs. And as at least one submission noted, there is no way to measure the social and economic cost of failing to ensure young people with disabilities have every opportunity to learn. Failing to provide them with an appropriate education limits their potential to lead productive, independent adult lives.

The majority of submissions strongly argued that the current system has little or no capacity to meet the learning needs of students with disabilities and lacks the resources to ensure their full participation in classrooms and schools. The frustration of parents is captured in the following submission.



I am the mother and primary carer of our 13-year-old son, B who has a diagnosis of Aspergers Syndrome. B has complex care needs. B is at home full-time as we have been unable to enrol him in a school-based setting. A great part of my day involves teaching B. Part of the care I provide involves managing challenging behaviour. Many of B's self-strategising mechanisms have been removed from him. When in early primary school years B would hide under tables (fright response)... he was punished by teachers for this behaviour.

Our experience has found that an education professional's inability to act appropriately to behavioural responses in children with special needs stems from a lack of knowledge of the needs of those with a disability and/or attitudinal beliefs. We are often judged as having poor parenting skills, our son judged as a badly behaved child. We have even been accused through innuendo and inference by school staff of abusing our son, despite him having a formal diagnosis of an ASD [Autism Spectrum Disorder]. These are individuals to whom we entrust the care and wellbeing of our children for a large part of the day. If those who should know better are judgemental ... how can we ask wider society to act differently?

Fundamentally, B is home due to systemic issues. In short the system has failed and continues to fail our son. [We are unable] to transfer our son's \$17,500 per annum integration funding package from his Government Secondary School setting to his Government Distance Education School. The system and society assume that we are willing to accept second best or the bare minimum. This is not the case. I want the best possible outcomes for my children. As a carer, I need this to be recognised through the provision of appropriate supports and programs.

A mandatory and extensive professional development program for education professionals needs to be set in place for practicing teachers. A mandatory component on disability must be introduced to all teacher training programs.

Most submissions said that there is a pressing need to provide more extensive resources to ensure the learning needs of children with disabilities are met. Many submissions passionately argued that a lack of adequate funding in mainstream schools forces parents to seek alternatives. Lack of support for inclusion, for example, may drive parents into choosing specialist settings despite their desire for their child to attend local schools.



Whilst government policy talks about the choice of regular class, support class or special school, students with a significant disability are usually forced to attend a special school even where inclusion is the expressed wish of the parent.

Other submissions argued that the inflexibility and lack of portability of funding has narrowed their choices. Many parents said, for example, that the lack of assistance and support in independent and faith-based settings has constrained their ability to choose these school settings for their children.

Greater resources are required to ensure a child's full participation not only in the classroom but in all aspects of school life, including excursions and sporting and cultural activities. One consultation participant recounted the story of a family who was told that their child would not be able to attend school excursions because the school was not willing to hire a bus with wheelchair access.

But problems with the system clearly go beyond a lack of resources. A number of submissions argued that there seems to be a systemic lack of commitment to inclusion and a widespread lack of understanding of its benefits. This lack of commitment translates not only to a lack of resources, but also to a lack of attention to teacher training and professional development. Parents were frustrated that too few teachers appear to be well equipped to deal with the full range of learning needs in their classrooms. As one noted,

“ My daughter's two physical ed teachers ignore her totally, [and] as a consequence, I have withdrawn her from these classes. She was sad and bored with being taken around the block or playing ball with an aide. The teachers were not made accountable for this in any way.

One aide refuses to turn my daughter's communication device on saying they do not have the time.

The 'integration/inclusion co-ordinator' position needs to be a senior teaching and school leadership role taken by someone who understands the curriculum and meeting a diverse range of learning needs.

One submission argued that fundamental systemic change will only be achieved when there is a shift in school culture and a change to teacher training as well as an increase in resources. This submission argued,

“ A shift in school culture to a focus on individual learning needs and investment in the development of innovative teaching strategies will ensure all students are provided with the opportunity and means of learning. There is also a need to promote the benefits of inclusive education not only to schools but also the broader community so that teachers, principals and parents have their concerns addressed and fully understand the advantages to all students.

Submissions noted that almost every report on the issue of inclusive education in Australia has stressed the need for systematic strengthening of teacher education and professional development. Skills development is the single most cost-effective method of improving outcomes for students with disabilities, and yet this area continues to

be neglected. Submissions identified lack of teacher training as one of the reasons so many schools are reluctant to include children with disabilities in their classrooms. If teachers feel their training has not adequately prepared them for the many challenges of the classroom, and that little additional assistance is available to support them, they will be less likely to embrace the concept of inclusion. And as the respondent below notes, frustration with the system is not confined to parents.

“ “ As a classroom teacher I enjoy having students with a disability in my mainstream classroom as I see them as children first. However, it is extremely frustrating and discouraging to see a child needing a particular intervention or program and being unable to provide it properly because there is no one there to give the child the extra support they need.

A number of submissions also highlighted the failure of the system to adequately prepare students for post-school life. Being regularly engaged in meaningful activity such as employment, vocational training or higher education is key to moving towards an independent adult life. Low participation rates in higher education, training and employment would suggest that few young people with disabilities are able to access the support required to successfully make this transition. Most submissions in this area noted the absence of comprehensive individualised planning that would allow young people to make meaningful choices about their lives after school. Parents reported confusion about the range of options and support available, and the difficulty in negotiating eligibility requirements and processes. They reported frustration at being forced to cobble together solutions when gaps became all too obvious. Other submissions noted that for young people with significant or complex support needs, there appear to be few satisfactory post-school alternatives.

Families consistently reported that their children had slipped through the cracks of the system after formal schooling ended. As one respondent noted,

“ “ Inclusion is at least philosophically supported in the education system in this state but when the young adults leave the school there is simply no expectation that they will follow a path that might assist development or lead to a meaningful job or way of life.

Another expressed frustration at the complexity and inconsistency of the support system.

“ “ Because she is now 16-years-old I have had the disability allowance discontinued even though she is still at school for another two years! She is unable to take out private health insurance because she is too young ... but she doesn't meet the criteria for a pension.

Similar frustration was expressed by the family of a young person with muscular dystrophy.



Because he was over 16 the Child Disability Allowance was stopped. J was an ‘adult’ for Centrelink and employment purposes, a ‘child’ by law and for private health insurance — the list goes on. J can work over 15 hours per week—so no Disability Pension; no Youth Allowance because his parents’ combined income was over the ‘magic’ number. He had to fight lots of red tape to receive the Mobility Allowance, his only source of income for a very long time. This was a very traumatic time for J as he wanted to become independent and at least work part time ‘like the others’. It would have been better if J had automatically received either the Disability Pension or Youth Allowance/Mobility Allowance and access to services immediately from leaving Year 12.

### Proposed solutions

Almost all submissions identified the need for greater funding for truly inclusive education to be achieved. They argued that adequate funding should be provided regardless of the choice of school setting.



All children and young people are entitled to an adequate level of government funding to improve their access to education regardless of the pre-school, school or school sector they attend.

Beyond greater resourcing, most submissions also strongly supported improved teacher training and more targeted professional development. Both undergraduate training for new teachers and professional development for existing teachers should draw on national and international research on best practice as well as capturing innovative and successful strategies in schools around the country. A number of submissions also noted the need for more research into effective strategies and programs and the creation of national benchmarks and standards. Both would provide a solid foundation for more extensive teacher education.

Most submissions that addressed the transition of students to post-school options focused on the pressing need for comprehensive individualised planning. These submissions noted that planning must be strategic and timely in order to be truly effective. For particularly vulnerable students, advanced planning was seen as crucial. One submission suggested, for example, that students with disabilities should begin work experience during the early years of high school, with the amount of time spent at work increasing as they move through their secondary schooling. Another submission suggested creating a targeted university program similar to Abstudy to increase participation rates in higher education.

## 2.7 'ISOLATED AND ALONE'— THE SOCIAL EXPERIENCE OF DISABILITY

### 2.7.1 THE IMPORTANCE OF RELATIONSHIPS — THE SOCIAL NEEDS OF PEOPLE WITH DISABILITIES

“ The [Home and Community Care program] guidelines are based on the income of the person who shares your home with you. I had to get rid of my housemates in order to get extra HACC assistance. I had male housemates and I was told they were expected to help care for me, e.g. food, cleaning, shopping, everything! But none of these people were my partner, they were just housemates, and they were male—how could I expect them to help me shower or go to the toilet? So I was forced into sole living because of the HACC guidelines.

It was clear from the submissions that too many people with disabilities in the community are isolated and lonely. For some, the barriers in the built environment limit their ability to participate fully in community life. But for others the barriers are social and attitudinal. It is these barriers that have proved the most difficult to overcome.

Few can appreciate the impact of exclusion and profound isolation on the identity and self-esteem of people with disabilities. Always defined as 'different', always defined by lack—many people spoke movingly of the impact of being defined by others. When identity is always framed by others and always framed in a negative way, it is difficult to develop and maintain a strong positive sense of self and difficult to establish and maintain relationships characterised by equality and mutual support.

The opportunity for marginalised groups to come together around a shared experience of oppression and exclusion has been a key strategy in the fight for social change in other areas. Social movements such as feminism have recognised the importance of identifying and detailing shared experiences in order to advocate for change. As a number of submissions noted, this is no less true for people with disabilities.

“ The ability for people with a disability to come together around the lived experience of disability is important for both the development of advocacy as well as the development of a strong sense of identity. The importance of peer support extends beyond people with an intellectual disability to those who support and care for them. Peer support plays a critical role in building resilience. Overseas research demonstrates that families consistently value peer support over support provided by professionals. The National Disability Strategy should therefore recognise the valuable role of peer support in building resilient individuals and families.

A number of submissions suggested that people with an intellectual disability particularly struggle for meaningful engagement with the community. Powerful taboos around relationships and intimacy still hamper the ability of people with an intellectual disability to make meaningful connections and enjoy the same rights as others in the community. As a result, they are among the most isolated groups. One submission powerfully illustrated the difficulties.



Over the last several years D has made many friendships with other young adults. Their friendships have developed into boyfriend girlfriend relationships. On many occasions D has asked these young females to go to the movies, go away for a weekend, come on holiday with him or attend music concerts. There has been the occasional time when one of these young females has been able to participate in these experiences. It has been marvellous to see these young adults behaving like other young adults. Holding hands, eating a meal at a restaurant, swimming at the beach.

But in the majority of cases, when D has reached out to the young females, (who always express positive interest in spending leisure time with him), the parents have intervened with rather inadequate explanations. 'Oh ... oh no we are going away that weekend ... sorry' or 'Xxxxx is too busy on weekends, sorry she doesn't have the time ...' When I have been with D when he has asked these young females, it is clear they want to engage in more leisure time with him. And yes, it is most likely if they continued with these extended leisure times, then intimacy would most likely occur.

We have tried to make contact with the parents and discuss these leisure options but it's nearly always a closed shop. I understand contraception could be a concern, but there are many options in this area and it can be managed.

We are not sure how to address the issue. Surely these young adults have the right to engage in human relationships and derive the same benefits we have all received from being able to share in an intimate and loving relationship.

This submission suggested that education of families and the broader community is key to ensuring young people with an intellectual disability have the opportunity to develop meaningful relationships, including the possibility of intimacy.



## 2.7.2 THE IMPORTANCE OF RELATIONSHIPS — THE EXPERIENCE OF FAMILIES AND CARERS

“ As a law graduate and a practicing financial analyst I was a productive and contributing member of Australian society. I returned to work after both my pregnancies ... Returning to work after my third child was very difficult, and continuing became impossible. The government did nothing to help. Medical practitioners were reluctant to deliver a diagnosis, which left us in the dark. I have cared for my son full-time for the last decade. The journey since then has been long and hard, and will only end in my son’s death.

“ Many people with a disability continue to depend on family carers as their main source of support. There is a lack of facility-based respite available for parents and carers of people with a disability and carers are at risk of suffering physical and mental health problems if adequate supports are not put in place to enable them to effectively care for their relatives. A flexible and affordable range of options needs to be made available to carers as a matter of urgency.

Not all people with a disability have or need a carer. But for those who do, families and unpaid carers provide the majority of the care. For too many people with disabilities, quality of life is dependent on the commitment of families. These families provide somewhere for their family member to live, take them to activities, search for suitable services and programs, advocate for change and stand up for their rights. They make sacrifices to the family budget to ensure their family member with a disability has what they need for a meaningful, participatory, independent life. In short, many families fill the very real gaps in the service and support system.

“ My daughter has a profound and complex disability. She needs specifically trained carers to help her eat, to go to the toilet and for communication. The services provider has not supplied this adequately—outsourcing rosters to other agencies as they cannot provide a worker, so consequently we do not get the specifically trained ones. This in real terms means my husband and I are obliged to take on these tasks. This means that often we have to cancel plans for a break, or short respite or a special event we had hoped to go to. I am required to pick up the tab every time the service provider falls short.

As the submissions made abundantly clear, families do not resent the care and support they provide—their love and devotion to family members was evident on every page. But they are angry when they feel that care is taken for granted and exploited to reduce costs.



I love my daughter. I want the same things for her as I want for my other children. I want her to have a good education, somewhere for her to live, meaningful work that she enjoys, a circle of family and friends who love her, someone for her to share her life with. But I lie awake at night worrying about how I can make all that happen. She is only eight, and I have already twisted myself into a pretzel trying to make sure she has all she needs. We pay for everything ourselves and we don't get any government support. I can't do it all alone.

Most submissions argued that if some of the very pressing needs of people with disabilities were addressed, the responsibility for support would not fall so heavily on families. While submissions recognised that the National Disability Strategy should focus on people with disabilities, many argued that it should also recognise the importance of the support provided by families, friends and carers. These submissions argued that greater support for families is essential to ensuring people with disabilities have every opportunity to reach their full potential and participate meaningfully in the life of the community.

The lack of appropriate and flexible respite was a particular concern. A number of submissions argued that respite is essential to ensuring that the physical and mental health needs of carers are met and that they are able to continue to provide care and support.

Submissions also highlighted the needs of ageing carers still providing extensive support to a family member with a disability. These submissions noted that a lack of services and out-of-home accommodation can restrict the ability of these families to plan for a successful transition out of the family home. Both carers and family members with a disability are haunted by the fear of what will happen when the carer is no longer able to provide an appropriate level of support.



I sometimes feel so guilty because mum and dad have given their lives to support me and without much government funding. Over the years they have faced discrimination and not much support from our local community. I can't remember when they had a holiday. People just do not understand. Now I see them getting older and I wonder what will happen to them and to me.

## Proposed solutions

Proposed solutions focused on the need for improved service delivery to people with disabilities. Most submissions welcomed the introduction of individualised funding packages and argued that greater availability will help to ensure that services and supports are tailored to individual family needs. Submissions also called for improved information and support for families and carers accessing services. Some suggested the creation of a specific service—a ‘one-stop shop’—where people with disabilities and their families, friends and carers could access information about services and programs, staffed by appropriately trained people who could better explore the needs of individuals and their families. Other submissions noted that individuals, families and carers would be better served if bureaucracy and ‘red tape’ was reduced.

Most submissions that discussed the needs of families and carers spoke of the importance of respite. These submissions argued that respite ensures that families are able to continue to support their family member and enables their increased participation in both the workforce and the community. Respite ensures that families are better able to sustain the caring role and balance work and caring responsibilities. These submissions noted, however, that in order to be effective, respite must be flexible and tailored to the needs of individuals and their families.

The physical and mental health needs of carers was also addressed by a number of submissions. They argued that greater attention to the particular needs of carers is warranted, particularly in the area of injury prevention. A number of participants at consultations spoke about the need for routine availability of grief and loss counselling for families with a member with a disability, particularly following a new diagnosis.

Most submissions welcomed the fact that carer allowances and payments had been included in current government inquiries into income support. But many noted that issues for carers go beyond the scope of these inquiries and argued for greater attention to issues such as access to superannuation for full-time carers.

## 2.8 THE EXPERIENCE OF DISADVANTAGED GROUPS

While only a small number of submissions were received from groups or individuals regarding the particular concerns of Aboriginal and Torres Strait Islander people and people from multicultural backgrounds, many more people actively participated in face-to-face consultations across the nation (see Appendix C). These consultations made it abundantly clear that there are issues specific to these groups that must be addressed in the National Disability Strategy.

## 2.8.1 PEOPLE WITH DISABILITIES FROM A MULTICULTURAL BACKGROUND



I care for a mother with a psychiatric disability. My mother is from a Greek background. I remember my mother experiencing barriers in participating in social events with her extended family due to the medication she was taking making her drowsy and unable to concentrate and communicate with her peers. I was too young at the time to do anything about it. I would just watch as it happened that she was excluded from the main table of events and left sitting alone for long periods during parties. What would have helped at the time is if we as a family found some other medication she could be taking to make her more communicative.

As I got older I was able to speak up and change doctors to put her on a newer type medication, which made her more social. My father was unable to do this due to language barriers and he only accessed a GP—at the time he knew nothing of community mental health centres. He did not have any information in his own language about where to go for help. It would have been good if these were accessible in the library or public places where he could pick it up unobtrusively. It always hurt to see mum excluded because of her disability.

There needs to be more support groups in different languages for consumers and carers state by state. Also recreational groups make a big difference to feeling socially connected.

People with disabilities and their families, friends and carers from a range of cultural backgrounds often have to deal with multiple issues on multiple fronts—their cultural background can act to complicate and compound issues associated with disability.



For families from different ethnic backgrounds, the issues are compounded. Many people from different ethnic backgrounds are not aware of their rights—to benefits, services, supports or respite. Due to the isolation felt by many carers and people with a disability from different ethnic backgrounds, language barriers or low levels of English proficiency still mean that these families do not access information and are unaware of what is available.

Most noted that few disability services possess the skills or resources to meet the specific needs of people with disabilities from differing backgrounds, and their relative inexperience with different cultural groups can make them insensitive to the issues involved. On the other hand, programs and services targeted at different cultural groups do not always understand the issues facing people with disabilities and their families, friends and carers. Respondents therefore strongly argued for increased funding for support programs and services for multicultural groups. They also argued for greater availability of translator services and information in a range of languages to ensure people with disabilities and their families, friends and carers are able to understand their rights and eligibility for services. Programs and organisations providing disability services require improved education and training about the needs of people from different cultural backgrounds.

## **2.8.2 PEOPLE WITH DISABILITIES AND ABORIGINAL OR TORRES STRAIT ISLANDER IDENTITY**



The NDS [National Disability Strategy] as one of its first principles should acknowledge Aboriginal and Torres Strait Islanders as the original inhabitants of Australia and the custodians of the land. The Strategy should acknowledge the destruction of Aboriginal and Torres Strait Islander communities that occupation of Australia has produced. This destruction and the resulting dislocation and alienation is the primary contributor towards disability in Aboriginal communities. The NDS should commit to additional measures to support Indigenous people with a disability.

Like people with disabilities from a range of cultural backgrounds, people with disabilities from an Aboriginal or Torres Strait Islander background feel they face a 'double disadvantage'. Aboriginal and Torres Strait Islander people suffer significantly worse health outcomes in all reported areas and fare worse than non-Indigenous people on all measures of social and economic disadvantage. While there is now considerable attention focused on finding ways to 'close the gap', participants at consultations argued that additional attention must be given to the particular experiences and needs of Aboriginal and Torres Strait Islander people with disabilities.

Participants at consultations reported that few disability service providers seem to grasp the complexity of the issues confronting Indigenous people. As a result, services and programs are rarely culturally sensitive or appropriate. Alternatively, mainstream services targeting Indigenous people do not always understand the issues facing individuals with disabilities and their families.



Non Aboriginal services do not understand the Aboriginal way of 'shared care' and the role that extended families play in supporting Aboriginal people with disabilities.

The chronic lack of services in regional and remote areas not only restricts choice but sometimes means people are forced to leave their communities in order to access services and support.



The lack of renal facilities in rural communities has meant people have had to move to larger cities in order to stay alive. For some people this means onerous and expensive travel over several days of the week. For others, particularly in Indigenous communities, it has meant the dislocation of families to enable the person to receive treatment. An Aboriginal man who was a leader in his community was overnight told he had to move to Alice Springs. The impact not only on the man and his family but on his community at large has been huge. To have a significant leader leave on what probably will be a permanent basis causes severe disruption.

Like other people with disabilities, Aboriginal and Torres Strait Islander people with disabilities face particular problems in education, employment, health care, transport and housing. These difficulties are compounded by entrenched racism and the often remote location of communities. The importance of greater availability of transport to improve access to health care and other services and support was a recurring theme at consultations. Participants also suggested that the specific needs of carers from Aboriginal and Torres Strait Islander backgrounds are often neglected, and there is a pressing need for greater availability of respite. Participants noted that it is often difficult for people with disabilities to participate fully in important cultural activities. Aboriginal and Torres Strait Islander people with disabilities who want to be full and active participants in the life of their community often find themselves isolated and excluded.

Participants noted that despite obvious expertise and experience, Aboriginal and Torres Strait Islander people rarely have the opportunity to have meaningful strategic input into the design and management of services and support.



The lack of access of Aboriginal and Torres Strait Islanders with a disability to effective advocacy and representation entrenches and perpetuates the structural discrimination we face. Moreover, the absence of such advocacy and representation, and the presence of advocacy and representation for other population groups has a compounding negative distributive impact on Aboriginal persons with a disability. Effective advocacy and representation for other groups results in a progressive distortion of resources away from Aboriginal persons with a disability.

One submission therefore suggested using Aboriginal and Torres Strait Islander disability networks in regional centres to provide support, education and training for mainstream services to better address the needs of Aboriginal and Torres Strait Islander people.

### **2.8.3 DISABILITY AND GENDER**

More than 15 per cent of submissions highlighted particular issues facing women with disabilities. In addition, a number of regional consultations specifically targeted women with disabilities. The issue of violence against women with disabilities was, sadly, a recurring theme. Submissions noted that women with disabilities escaping family or domestic violence are not well catered for within mainstream support organisations and services—most notably in the Supported Accommodation Assistance Program (SAAP) emergency accommodation. Submissions and participants therefore urged greater liaison with other Commonwealth initiatives such as the National Plan to Reduce Violence against Women and their Children and the National Homelessness Strategy to ensure proposed strategies, programs and services are responsive to the particular needs of women with disabilities. A number of submissions also argued that there is a pressing need for greater research into the experience of women with disabilities to inform the development of more appropriate strategies and resources.

### 3 CONCLUSION — IMPLICATIONS FOR THE DEVELOPMENT OF THE NATIONAL DISABILITY STRATEGY

The significant number of submissions and the large number of people who took the time to attend public consultations across the country are a strong indication of the depth of feeling among people with disabilities and their families, friends and carers. While desire for change ranged from impatience to desperation, all participants made it abundantly clear that much is expected from the National Disability Strategy. Piecemeal reform will not suffice. The message from all participants was that systemic reform is necessary and long overdue.

From its review of the submissions and consultation transcripts, the National People with Disabilities and Carer Council believes that the National Disability Strategy should serve as an overarching policy statement, setting the national view, establishing future directions and identifying priorities for people with disabilities and their families, friends and carers. It should address four strategic priorities:

- increasing the social, economic and cultural participation of people with disabilities and their families, friends and carers
- introducing measures that address discrimination and human rights violations
- improving disability support and services
- building in major reform to ensure the adequate financing of disability support over time.

While details varied, most submissions agreed that the strategy should consider the following key features:

- adoption of a coordinated national approach to enhance consistency across jurisdictions
- development of underlying principles that reflect the *UN Convention on the Rights of Persons with Disabilities*. Many submissions made it clear they expected the National Disability Strategy to realise the rights enshrined in the Convention. Without a strong strategy, many participants feared that the Convention would fail to change the lives of Australians with disabilities and become just another piece of meaningless rhetoric
- creation of an Office of Disability to coordinate efforts across portfolios and between levels of government
- implementation of policies under the strategy by each level of government and all government agencies, with clear outcomes and performance measures
- provision of funding increases to advocacy and other non-government agencies to participate in monitoring and evaluation of the strategy.



The National People with Disabilities and Carer Council believes that the National Disability Strategy represents the first time in this country that disability policy will be underpinned by a whole-of-government, whole-of-life approach. In outlining a high-level strategic vision, it will ensure that there is coordinated and comprehensive planning across all portfolios and between all levels of government. In developing the strategy, governments will consider how current disability and mainstream policies, programs and services operate, how they can work together more effectively and what new initiatives are needed.

Importantly, the strategy will recognise the complexity of people's lives and the intersection and interdependence of many areas. The strategy will recognise, for example, that the effectiveness of reform in one area will be limited if issues in another area are left unaddressed. The strategy will also recognise that people with disabilities and their families, friends and carers are not a homogeneous group, and that different strategies may be required to address the specific needs of some groups. The challenge for the strategy is to also acknowledge and address sometimes conflicting perspectives and negotiate a path forward.

While adopting a national approach, the strategy will also ensure that each level of government retains the flexibility to respond to the sometimes unique characteristics, priorities and challenges of their individual jurisdictions.

It is also important to note that the National Disability Strategy will not and cannot be seen in isolation. The Australian Government has also undertaken to analyse how the strategy will complement work being carried out as part of a number of other key government initiatives and reviews, including (but not limited to) the following:

- Disability Investment Group report
- National Disability Agreement
- National Mental Health and Disability Employment Strategy
- National Action Plan for Mental Health 2006–2011
- Harmer Pension Review
- Inquiry into Australia's Future Tax System
- Disability Standards for Education (2005)
- Disability Standards for Accessible Public Transport (2002)
- House of Representatives draft Disability (Access to Premises—Buildings) Standards
- House of Representatives Inquiry into Better Support for Carers
- National Arts and Disability Strategy
- National Plan to Reduce Violence against Women and their Children
- National Homelessness Strategy
- Harmonisation of Disabled Persons Parking Scheme and Companion Card Scheme

- AusAID's Disability Strategy: 'Development for All'
- Government departments' Disability Discrimination Act Action Plans
- Aviation Access Working Group
- Inquiry into Access to Electronic Media for the Hearing and Vision Impaired.

The findings contained in this report will now feed directly into the development of the National Disability Strategy. Throughout 2009-10 the Australian Government will continue to work in partnership with state and territory governments and the National People with Disabilities and Carer Council, and through discussions with government departments, agencies and other stakeholders. Critical thinkers and subject experts will be brought together to develop innovative strategies and actions to tackle identified priorities in each area along with appropriate outcomes and targets. And most importantly, an evaluation, monitoring and reporting process will be developed as a means of tracking the progress of the strategy to ensure real and meaningful change is achieved. Overseas experience suggests that the effectiveness of the strategy will be boosted by the creation of a strong monitoring and reporting framework. The Australian Government will develop an evaluation process in consultation with the state and territory governments, and this will contribute to the Government's biannual reporting on progress against the *UN Convention on the Rights of Persons with Disabilities*.

The strategy will be released mid-2010 and will have a ten-year life span, with review points after two and five years.

But it is also true that governments cannot work in isolation. Real long-lasting change will only be achieved in partnership with business and the community. Participants and submissions made it clear that people with disabilities and their families, friends and carers expect the government to bring everyone together to work towards a common vision. And they are hopeful. They want others to share their vision and recognise the benefits for all in building more inclusive communities. The challenge is for everyone—governments, businesses, communities and individuals—to think about and do things differently. But the process has already begun—the innovative ideas and solutions presented in this report are just one place to start. Now that the national conversation has started, there are bound to be many more.

There are many challenges on the road ahead. The complexity of the issues faced by people with disabilities and their families, friends and carers, and their long history of marginalisation and exclusion, means change cannot be achieved overnight. But the National Disability Strategy represents an important step in closing the gap between the lived experience of people with disabilities and the rest of the Australian community and ensuring that people with disabilities finally have every opportunity to fully participate in the social, cultural and economic life of the nation.

# APPENDIX A

## QUESTIONS FROM THE DISCUSSION PAPER

### **1. WHAT DO YOU THINK SHOULD BE INCLUDED IN THE NATIONAL DISABILITY STRATEGY?**

- What are the greatest barriers that people with a disability face to participating fully within the community and what specific local or national actions could be taken to overcome these barriers?
- What areas of research do you think should be a priority to better inform the National Disability Strategy?

### **2. WE ARE INTERESTED TO KNOW ABOUT YOUR PERSONAL EXPERIENCE**

- Please tell us in your own words about any time that you, or someone you care for or support, experienced barriers to participating in a community, social or work event.
- What local action has made a positive difference to your life or other people with disability, their families and carers?
- What local action has made a positive difference to the life of someone you care for or support?

### **3. DO YOU HAVE ANY OTHER COMMENTS, THOUGHTS OR IDEAS ABOUT THE NATIONAL DISABILITY STRATEGY?**

## **APPENDIX B**

# **LIST OF ORGANISATIONS THAT PROVIDED SUBMISSIONS**

Ability Employment Group Inc.  
Ability First Australia Disability Services  
Ability Options  
Ability Tasmania Group Inc.  
Ability Technology  
Aboriginal Disability Network NSW  
Aboriginal Disability SA (ADNSA) Committee, Department of Families and Communities, SA  
Acacia Court Talkback Group  
Accepting Engagement Pty Ltd  
Access and Inclusion  
Access For All Alliance  
Access Innovation Media  
Accessible Arts  
ACE Representing Australia's Disability Employment Network  
Action for Community Living Inc.  
Action for More Independence and Dignity in Accommodation Inc.  
Action of Disability within Ethnic Communities Inc.  
Activ Foundation Inc.  
ADDults with ADHD (NSW) Inc.  
Advocacy for Inclusion  
Advocacy Tasmania Inc.  
Aged and Community Services Australia  
AGOSCI Inc.  
Aids and Equipment Action Alliance  
Albury and Wagga Wagga Vision Australia  
Allergies and Intolerant Reactions Association  
Allergy and Environmental Sensitivity Support and Research Association Inc.  
Allergy, Sensitivity and Environmental Health Association Qld Inc.

Alzheimer's Australia  
AMPARO Advocacy Inc.  
Anglicare Victoria  
Arts Access Australia  
Arts Disability Leadership Innovation  
ASEHA QLD Inc.  
Association for Children with a Disability  
Association of Independent Schools of South Australia  
Attendant Care Industry Association of NSW Inc.  
Australasian Faculty of Rehabilitation Medicine  
Australian Aphasia Association  
Australian Association for Families of Children with a Disability  
Australian Association of Social Workers  
Australian Communication Exchange Ltd  
Australian Confederation of Paediatric and Child Health Nurses – NSW Branch  
Australian Council of Social Service  
Australian Council of Trade Unions  
Australian Deafblind Council  
Australian Domestic and Family Violence Clearinghouse  
Australian Federation of Deaf Societies  
Australian Federation of Disability Organisations  
Australian Human Rights Commission  
Australian Network for Universal Housing Design  
Australian Physiotherapy Association  
Australian Psychological Society  
Australian Rehabilitation and Assistive Technology Association  
Australian Sign Language Interpreters' Association National Inc.  
Australian Social Inclusion Board  
Autism Aspergers Advocacy Australia  
  
Back to Back Theatre  
Barkuma Inc.  
Bedford  
BEST Community Development  
Bethany Community Support

Better Hearing Australia Central Coast Inc.  
Beyond Blue: The National Depression Initiative  
BHA – Sunshine Coast  
Bindi Inc.  
Blind Citizens Australia  
Bowden Brompton Community Group Inc.  
Brain Injury Association of Tasmania  
Brain Injury Australia  
Brain Injury Network of SA Inc.  
Brain Injury Rehabilitation Unit  
Brimbank City Council  
Brotherhood Community Care – Southern  
Bus and Regional Services Branch, Public Transport Division, VIC  
Camp Autism  
Camperdown Mental Health Service  
CAN (Mental Health) Inc.  
Care Connect Limited  
Carer Support and Respite Centre  
Carers Australia  
Carers' Link  
Carers WA Inc.  
CD in Motion  
Cerebral Palsy League Queensland  
Challenge Disability Services  
Chamber of Commerce and Industry  
Children and Young People and Child Guardian  
Children and Youth Services Therapy Focus Inc.  
Christie Centre Inc.  
City of Boroondara  
City of Darebin  
City of Melbourne  
City of Port Phillip  
City of Salisbury

City of Whittlesea  
City of Yarra  
Clubs Australia  
CNC Disabilities – Royal District Nursing Service of SA  
CNM Acquired Brain Injury Rehabilitation Unit  
Coffs Harbour and Bellingen Local Disability Advisory Committee  
Communication Disability Centre – Postgraduate Coordinator  
Community and Allied Health Services  
Community Living Association Inc.  
Community Options Programme  
Computer Club for People with Aphasia  
Consumer Advisory Group – Mental Health Inc, NSW  
Consumers' Telecommunications Network  
Consumers' Health Forum, ACT  
Cosmos Recreation Services  
Counsellors and Social Workers Inc.  
CRS Australia

Darwin Respite and Brokerage Service Coordinator Anglicare, NT  
Deaf Australia Inc.  
Deaf Children Australia  
Deaf NT  
Deafness Forum of Australia  
Department for Planning and Infrastructure, WA  
Department of Ageing, Disability and Home Care, NSW  
Department of Education and Training, NT  
Department of Further Education, Employment, Science and Technology, Planning and Evaluation Directorate, SA  
Department of Health and Families, NT – Aged and Disability Program  
Department of Premier and Cabinet, TAS  
Department of Rehabilitation, Disability Action Plan Committee, The Children's Hospital at Westmead  
Dietician's Association of Australia

Directorate Victoria Legal Aid  
Disability Advocacy and Complaints Service of South Australia Inc.  
Disability Advocacy Network Australia  
Disability Advocacy Service  
Disability Council of NSW  
Disability Council of Queensland Secretariat  
Disability Discrimination Legal Service  
Disability Services Commission  
Disability Services Queensland  
Disability Training Program – Victims of Crime  
Disability WORKS Australia Ltd  
Disabled Motorists Association  
Disabled Surfers Association of Australia Inc.  
Diversity Council Australia  
Domiciliary Care SA  
Down Syndrome Victoria  
Down Syndrome WA  
  
Early Childhood Intervention Australia  
Early Childhood Intervention Australia (NSW Chapter) Inc.  
Early Childhood Services, Learning Links  
East Gippsland Shire Council  
Eastern Access Community Health  
EnableNSW – Health Support Services  
Endeavour Foundation  
Engineers Australia  
Ethnic Child Care Family and Community Services Coop Ltd  
Ethnic Disability Advocacy Centre  
Evans Community Options  
  
Faculty of Education, Health and Science, Charles Darwin University  
Fairholme Disability Support Group Inc. (WA)  
Family Advocacy  
Family Planning NSW  
Farrellys Lawyers



Federation of Ethnic Communities' Councils of Australia  
Fragrance and Chemical Sensitivity Support Group  
FRANS Inc.  
Funktion – Making Life Fit  
  
Gippsland Carers Association Inc. and Victorian Liaison – National Carers Coalition  
Gold Coast City Council  
Griffith University  
Guaranteeing Futures (South East)  
Guardianship Tribunal  
Guyrow Pty Ltd  
  
Hawkevale Trust  
Hear and Say Centre – Hear and Say Worldwide  
Help Darling Downs Inc.  
Hobsons Bay City Council  
House with No Steps  
Housing NSW  
Hume City Council  
  
Information on Disability and Education Awareness Services (IDEAS) NSW  
In Control  
Inability Possibility  
Inclusion Works  
Independent Advocacy SA Inc.  
Independent Advocacy Townsville  
Independent Lifestyle Solutions (TAS)  
Independent Living Centre of Western Australia  
Independent Rehabilitation Suppliers Association  
Interact Australia  
Interwork Ltd  
  
JMM Associates Pty Ltd  
Julia Farr Association

Kevin Heinze Garden Centre Inc.  
Kingaroy TAFE

Latrobe City Disability Reference Committee  
Latrobe Community Health Service, Moe  
Leadership Plus  
Legacy NSW, People with Disabilities Advisory Committee  
Legal Aid Queensland  
Life Tech Queensland  
Life Without Barriers  
Lifestart Co-operative Ltd  
Lifestyle in Supported Accommodation Inc.

Macarthur Disability Services  
Mamre Association Inc.  
Manning Gardens Public School  
Mansfield Shire Council  
Maribyrnong City Council  
ME/Chronic Fatigue Syndrome Society of NSW  
Media Access Australia  
Melba Support Services  
Mental Health Coordinating Council  
Mental Health Council of Tasmania  
Ministerial Advisory Committee: Students with Disabilities  
Montrose Access  
Moonee Valley City Council  
Mornington Peninsula Shire  
MS Australia  
Multicultural Disability Advocacy Association from NSW  
Multicultural Mental Health Australia  
Multiple Sclerosis Society of South Australia and Northern Territory Inc.  
Munchies International  
Municipal Association of Victoria  
Muscular Dystrophy - Tasmania

Nambour Aged Care Assessment Team – Queensland Government  
National Association for Conductive Education SA  
National Association of Childbirth Educators (SA)  
National Council for Women (QLD)  
National Council of Social Services  
National Council on Intellectual Disability  
National Disability Services  
National Ethnic Disability Alliance  
National Stroke Foundation (WA)  
Northcott Disability Services  
Novita Children’s Services Inc.  
NovitaTech  
NSW Association of the Deaf  
NSW Consumer Advisory Group  
NSW Council for Intellectual Disability  
NSW Disability Discrimination Legal Centre Inc.  
NSW Ombudsman  
NT Council of Social Services  
  
Office of Disability and Client Services, DFC  
Office of the Commissioner for Equal Opportunity  
Office of the Public Advocate (QLD)  
Onemda VicHealth Koori Health Unit  
OT Australia – Australian Association of Occupational Therapists  
Otto Bock Australia Pty Ltd  
  
Paediatric Brain Injury Rehabilitation Team  
Parents of the Hearing Impaired of South Australia  
Parkinsons Tasmania Inc.  
Penrith City Council  
People with Disabilities ACT  
People with Disability Australia  
Personal Advocacy Service  
Perth Home Care Services  
Physical Disability Australia Ltd

Physical Disability Council of New South Wales  
Pilbara Development Commission  
Play Environment Consulting Pty Ltd  
Playtas Pty Ltd  
Premier's Physical Activity Taskforce  
Private Mental Health Consumer Carer Network (Australia)  
PSE Access Consulting  
Public Interest Advocacy Centre Ltd  
People with Multiple Sclerosis (PwMS) (Vic) Inc.  
Queensland Parents for People with a Disability Inc.  
Real Living Options Association Inc.  
Reinforce Inc.  
RMIT University  
Royal Australian and New Zealand College of Psychiatrists  
Royal Children's Hospital  
Royal District Nursing Service (Victoria)  
Royal Flying Doctor Service – National Office  
Royal Rehab Aphasia Outpatient Group  
Royal Society for the Blind  
Royal Society for the Blind of SA Inc.  
Royal South Australian Deaf Society Inc.  
Ryde Area Supported Accommodation for Intellectually Disabled Inc.  
Salubrious Productions  
Samaritans Foundation  
School of Population Health – University of Melbourne  
Scope  
Senses Foundation  
Siblings Australia Inc.  
Social and Community Services, Manningham Council, VIC  
South Australian Taskforce on Multiple Chemical Sensitivity  
Southern Health  
Southern Tasmanian Youth Transitions Taskforce

Southern Therapy Service  
Spastic Centre  
Speaking Up For You Inc.  
Special Olympics Australia  
Speech Pathology Australia  
Spina Bifida and Hydrocephalus Association of SA Inc.  
Spinal Injuries Association  
SPLASH  
St George Association  
St Michaels Association  
Strategic Policy and Research Program, Commission for Children and Young People  
and Child Guardians  
Sunnyfield Independence  
Sunshine Coast Independent Living Service Inc.  
  
Tamworth Regional Council – Access Group  
Tangentyere’s Aged and Community Services, Tangentyere Council  
Telecommunications and Disability Consumer Representation  
Toowoomba and District MS Support Group  
Transport Victoria  
  
UnitingCare Community Options Victoria  
University of New South Wales  
University of Queensland  
University of Western Sydney  
  
Vicdeaf  
Victorian Coalition ABI Service Providers  
Victorian Council of Social Services  
Victorian Equal Opportunity and Human Rights Commission  
Victorian Mental Health Carers Network  
Victorian Parents’ Council  
Villa Maria  
Vision 2020 Australia  
Vision Australia

Waverley Industries Limited  
Wellington Shire Council  
West End Mental Health  
Western Australia Local Government Association  
Western Region Disability Network  
Western Sydney Intellectual Disability Support Group  
Westernport Speaking Out Inc.  
Whitehorse City Council  
Whittlesea District Adult Training and Support Services  
Witmore Training and Support  
Women with Disabilities Australia  
Women's Centre for Health Matters  
Workable Living  
YMCA Australia  
Youth Disability Advocacy Service (Youth Affairs Council of Victoria Inc.)

## APPENDIX C

# ABOUT THE CONSULTATION PROCESS

In announcing its commitment to the development of a National Disability Strategy, the Australian Government also pledged to ensure that people with disabilities and their families, friends and carers had a say in its creation. The aim of the public consultation process was to identify and explore the barriers faced by people with disabilities and their families, friends and carers in their day-to-day lives and to explore ideas about how these barriers could be broken down.

To help guide the community consultation process, the Australian Government produced a discussion paper. Launched on 17 October 2008 by the Hon Jenny Macklin MP, Minister for Families, Housing, Community Services and Indigenous Affairs, and the Hon Bill Shorten MP, Parliamentary Secretary for Disabilities and Children's Services, the discussion paper invited people to have their say by participating in a series of public consultations to be held across Australia and through written submissions.

The public consultations were held in all capital cities and in selected regional locations. The capital city consultations took place from 27 October to 26 November 2008 and were organised by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs. These consultations involved a wide range of participants, including individuals with a disability, parents of young and adult children with disabilities, carers, representatives from the disability services sector, non-government agencies, advocacy and lobby groups, business representatives, members of the National People with Disabilities and Carer Council, as well as officials from all levels of government. Table 1 provides the number of attendees at each location.

Each capital city consultation was chaired by Dr Rhonda Galbally AO, Chair of the National People with Disabilities and Carer Council. The council was established to provide expert advice and information to the Australian Government on the development and implementation of the National Disability Strategy. Through its membership, the council also provides a means for people with disabilities and their families, friends and carers to have an ongoing voice in the development of the strategy.

Fifty-two regional and remote area consultations were also held between October and December 2008 (see Table 2). These consultations were facilitated by the Australian Federation of Disability Organisations, and targeted specific groups, including people from Indigenous communities, people from multicultural backgrounds and women.

Due to the large number of submissions received, KPMG was engaged to conduct the preliminary analysis of the written feedback.

# TABLE 1

## CAPITAL CITY CONSULTATION SCHEDULE

City	Date	Number of attendees
Darwin	27 October	20
Sydney	5 November	120
Brisbane	6 November	116
Perth	10 November	62
Melbourne	12 November	190
Hobart	14 November	43
Adelaide	24 November	127
Canberra	26 November	92
<b>TOTAL</b>		<b>770</b>

# TABLE 2

## REGIONAL AND REMOTE COMMUNITY CONSULTATION SCHEDULE

State	Location	Date
NSW	Ballina	10 November
	Casino	11 November
	Coffs Harbour	18 November
	Condobolin	19 November
	Dubbo	18 November
	Grafton	12 & 19 November
	Lismore	20 November
	Newcastle	18 & 22 November
	Orange	12 November
	Tamworth	28 November
NT	Alice Springs	10 November
	Darwin	5 November
	Nyuntu Anangu Maruku Women's Council	10 November
QLD	Brisbane	6 November
	Cairns	20 November
	Hervey Bay	30 October
	Townsville	25 November



SA	Berri (Riverlands)	27 November
	Mt Gambier	28 November
	Port Adelaide	20 November
	Port Augusta	19 November
	Whyalla	18 November
TAS	Launceston	13 November
VIC	Ballarat	30 October
	Bairnsdale	26 & 27 October
	Bendigo	23 October & 19 November
	Cobram	23 November
	Melbourne	22 October
	Echuca	29 October
	Geelong	13 & 14 November and 9 December
	Horsham	30 October
	Melbourne	18 November
	Mildura	21 October & 18 November
	Mooroopna	18, 19, 20 & 29 October and 5, 14 & 24 November
	Portland	30 October
	Sale	26 October
	Seymour	20 October
	Shepparton	18, 19, 20 & 29 October and 5, 14 & 24 November
	Swan Hill	22 October
	Warrnambool	30 October
	Wodonga	22 November
WA	Bunbury	27 November
	Fitzroy Crossing	25 November
	Subiaco	26 & 28 November

forgotten...

neglected...

hidden...

rejected...

excluded...

discriminated...

abandoned...

isolated