

DISABILITY FUTURE DIRECTIONS 2025

Working at the interface

Stage One Report and Discussion Paper

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
CaLD	Culturally and Linguistically Diverse
CAP	Combined Application Process
COAG	Council of Australian Governments
Convention	Convention on the Rights of Persons with Disabilities
CSTDA	Commonwealth State Territory Disability Agreement
DAIPs	Disability Access and Inclusion Plans
DSC	Disability Services Commission
DEEWR	Australian Government Department of Employment, Education and Workplace Relations
DEN	Disability Employment Network
DHS	Australian Government Department of Human Services
DPI	Department for Planning and Infrastructure
EDAC	Ethnic Disability Advocacy Centre
FaHCSIA	Australian Government Department of Families and Housing, Community Services and Indigenous Affairs
HREOC	Human Rights and Equal Opportunity Commission
IPCC	Intergovernmental Panel on Climate Change
JCA	Job Capacity Assessor
NATSEM	National Centre for Social and Economic Modelling
NDS	National Disability Services Western Australia
NPP	National Partnership Payment
SPP	Specific Purpose Payments
SRV	Social Role Valorisation
RAP	Reconciliation Action Plan
UN	United Nations
VRS	Vocational Rehabilitation Services
WAPC	Western Australian Planning Commission
WHO	World Health Organisation

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Disability Future Directions 2025
STAGE ONE REPORT AND DISCUSSION PAPER

INTRODUCTION

Background

In 2007 the Disability Sector Health Check Committee recommended the development of long-term future directions for disability in Western Australia (WA), directions that would benefit all Western Australians with disabilities, their families and their carers. The process was to inform directions to 2025 within the community and key business corporations as well as the disability sector and related government agencies.

Stage One of the Disability Future Directions process involved an environmental scan to gather information about the economic, social and demographic trends likely to shape the future and impact on the lives of people with disabilities, their families and carers. This information was gathered in three main ways:

- A series of monographs was produced exploring current and future trends across a range of economic, environmental, demographic, social and institutional/governmental domains.
- People with disabilities, their families, carers and service providers were asked to consider the future and answer questions about their experiences, hopes and fears for that future. In order to get a wide range of opinions, consumer groups and agencies representing people of a range of ages, disabilities, geographical locations and cultural groups were approached. In addition, the National Disability Services in WA (NDS) and directorates of the Disability Services Commission (the Commission) were invited to share their views.¹²

¹ A total of seventy (70) individual and group responses to the eight questions were received: Non Government Agencies - 15 responses; Individuals, families, carers - 17 responses; Key Informants - 29 responses; Commission Directorates: 9 responses.

² An analysis of these interviews was prepared by Anne Banks-McAllister. Her work is drawn on throughout this report and gratefully acknowledged.

- A Disability Future Directions Think Tank was held on 29 August 2008 to consider:
 - the factors shaping society over the next 15 to 20 years;
 - the likely impact of each factor on people with disabilities, their families and carers;
 - the current capacity of individuals, families, carers, service providers, corporations and policy makers to adapt and respond to these factors;
 - the broad policy implications of these trends.

This report synthesises the data from these sources to highlight their strategic and policy implications for Disability Future Directions 2025.

Structure of report

The report falls into four main sections

Overview of Context

Drawing from the monographs, Think Tank and interviews, the report provides an overview of the economic, environmental, demographic and social factors affecting the development of Disability Future Directions 2025.

Five Principles

Drawing from the United Nations' (UN's) Convention and the discussions with individuals, families and stakeholders, the report proposes five principles to guide the next stage of discussions. These relate to the claim of each and every person to enjoy:

- Dignity and respect of person
- Economic security
- Comprehensive access and participation
- Cooperative planning and reciprocal dialogue
- Inclusion.

Attention is given to the theoretical significance and status of each principle, as well as the social and economic factors impacting on it.

Change: possibilities and barriers

Drawing extensively from the interview data, this section provides an outline of the factors affecting positive change.

Working at the interface

The final section proposes a framework within which Disability Future Directions 2025 might set priorities and organise strategies. It suggests that advantage be taken of the broad ranging nature of Stage One discussions by adopting an encompassing yet detailed approach to the Commission's Vision, spelling out and advancing the economic, social and environmental elements necessary to achieve a 'society in which all people live in welcoming communities which facilitate citizenship, friendship, mutual support and a fair go for everyone.'

It proposes that this is best achieved by 'working at the interface' – that is working at that point where the underlying trends discussed in the report impact directly on the lives of people with disabilities, their families and carers. In conclusion, it elaborates on the notion of 'conversations for change' as a means of progressing and supporting Disability Future Directions 2025.

Checkpoint reflections

Within the body of the report a series of 'checkpoint reflections' are provided, pointing to the main policy issues emerging from the discussion. These are should not be read as 'problems' that have to be 'solved' for Disability Future Directions to be successful. Many are deeply embedded in the prevailing social and economic structure and/or broader inter-governmental relations, nationally and internationally. They represent, rather, the challenges and realities that need to be taken into account as Disability Future Directions proceeds. It is in their context, and bearing them in mind, that the framework for deliberation, established in the final section of the report, makes sense. They are anchor points, reference points and reminders of reality.

Approach

The approach is broadly consistent with the social model adopted by the UN Convention, the World Health Organisation (WHO) and the Australian Institute of Health and Welfare (AIHW). This means that the focus is on the 'disabling' impact of the environment - that is, on those physical, social and/or cultural factors that limit a person's functioning. Hence it is a rights-based approach with the onus on policy makers to ensure that persons with impairments enjoy the same quality of life as everyone else. [For a comprehensive discussion of the ideological and conceptual changes involved see Samantha Jenkinson's (2008) monograph, *Local, national and international trends*]

However, disability academic and activist, Tom Shakespeare (2006, 2007), warns that this perspective can underestimate the extent to which significant impairments actually and practically affect a person's life. He argues against the polarisation between the medical and social models, suggesting instead we need to move towards a 'post-social' model that recognises both the problems caused by bodily and intellectual impairments and the complex interaction between these impairments and social/structural factors. In his words (2007):

I think that neither the 'medical model' nor the 'social model' provide the whole picture. Disabled people's lives are complex. Our limitations or difficulties of body and brain do cause us problems. Nobody wants their experience to be medicalised, but nor do we want to reject medicine. Equally, we want to challenge barriers and discrimination. In other words, people are disabled by society, and by their bodies. It is the interaction of individual factors - impairment, motivation and self-esteem - with external factors - the barriers, oppression and expectations and attitudes of other people - which combine to create the experience of disability.

Consistent with Shakespeare's point, the discussion of the five principles in the second part of this report is grounded in the embodied experiences of day to day living, under the head 'Dignity and respect of person'.

OVERVIEW OF CONTEXT

The information about present and future trends gathered through the monographs, interviews and Think Tank is summarised under four main heads:

- Climate change
- Economic trends
- Demographic trends
- Social inequality

Climate change

The main parameters of climate change are outlined in the monograph prepared by Stehlik and Costello (2008). The following aspects of their detailed account are particularly pertinent here:

- In its fourth assessment report, The Intergovernmental Panel on Climate Change (IPCC) (2007), recognises that global warming is unequivocal and can be expected to drive global patterns in rainfall, wind patterns and extreme events in ice distribution (Stehlik and Costello 2008: 6).
- The Stern Report (2007) emphasises that climate change threatens 'the basic elements of life for people around the world - access to water, food, health, and use of land and water environment (Stehlik and Costello 2008: 6).
- In Australia, modelling to date has predicted that, across the country, 'temperatures will rise, rainfall will change, sea levels will rise and that extreme events will become more frequent and intense. The combination of rising temperatures and decreased rainfall has major impacts on the forestry and agricultural sectors (Stehlik and Costello 2008: 7-8).
- Australia is particularly vulnerable to rising sea levels and coastal inundation and erosion - more than 80 per cent of the population living within 50km of the coast, with 50 per cent of these living within 7km and 6 per cent within 3km of the shore (Stehlik and Costello 2008: 7).

- Western Australia can be expected to experience increased temperatures, decreased rainfall, increased sea levels, and more heatwaves, droughts, bushfires, storms and tropical cyclones (Stehlik and Costello 2008: 9). The authors note that Perth and Adelaide are the Australian cities with water supplies most vulnerable to climate change.)

Following Spickett, Brown and Katscherian (2008), Stehlik and Costello (2008) suggest that vulnerability to climate change can be measured by considering:

- A group's exposure to the issue
- Its impact on them
- Their 'adaptive capacity' toward it.³

Stehlik and Costello's (2008: 11) take home message is clear:

We would argue that lessons from history teach us that it is likely that climate change adaption will become a class issue - where those with resources will be able to create their adaption and mitigation responses, and those who do not have resources, will suffer.

While climate change was not raised as a major issue in the interviews, the Think Tank raised extensive issues and concerns. Participants discussed rainfall changes, temperature increase and extreme weather events, drawing attention to their separate and combined effects on food production, health, diet, homelessness and desecration of landscape. For people with disabilities and their families, particular effects were noted in relation to:

- Major disruptions in fragile life patterns
- Increased cost of energy
- Increased cost of food
- Life-threatening events for people dependent on technology
- General exacerbation of existing health problems
- Social isolation if communication systems fail

³ If, for example, we were to consider the effect of heatwaves on people with core disabilities living in remote areas, we might consider their *exposure* in terms of location, the *impact* on their health and their *adaptive capacity* in relation to it (including house cooling).

- Increased cost of providing services.

On the positive side, the working group noted that climate change could lead to better contingency plans, the opportunity for renewal, resilience and community.

Checkpoint reflection

- What measures can be taken to promote disability friendly environments in regional, town and contingency planning?
- Can the public sector, the private sector and non-government providers promote the development of energy efficient housing able to withstand climate variability and extreme weather events?
- What about concessions on energy costs for people with disabilities?

Economic trends

In the introductory summary to his monograph, Michael Carroll (2008) reminds us that:

- Economic circumstances at all levels impact on people with disabilities.
- The wealth created by the economic boom has generally not benefited people with disabilities, their families and carers. This creates a 'double penalty', increasing the gap between rich and poor and making people with disabilities more vulnerable to the negative aspect of the boom, including rising costs across all sectors of the economy.
- Most economic modelling relies on an assumption that the immediate past will be somewhat similar to the future. Recent circumstances indicate that this is not the case. What is more reliable as a basis for modelling is the type of response likely to result from prevailing economic policy at the state and federal government levels given various economic scenarios.

Carroll's concerns were amply reflected in the interviews, where people frequently noted the growing gap between rich and poor and the rising cost of living. Representative comments suggested that:

- Cost of living will increase and impact on quality of life – greater disparity will exist between different social groups.
- In regional WA infrastructure is unable to keep pace with boom times, which leads to fractured families and inflated costs – unaffordable housing and high cost of living.
- Not everybody will benefit from the resources boom and there will probably be bigger and bigger gaps between the rich and those who are the working classes.
- We are in a boom but there are no services – the boom is creating a two-tier town.
- The impact of the economic boom dividing community into rich and poor.
Government seems to pour resources into economic boom not social needs.

The impact of economic inequality was also extensively discussed at the meeting between the staff from the policy section of the Disability Services Commission, the authors of the monographs and the research consultant. Particular emphasis was given to the impact of the cost of living and/or economic volatility on:

- Financial insecurity
- Physical well being
- Who can provide care and at what cost
- The range of services universally available.

Think Tank participants reached similar conclusions, emphasising the impact in terms of personal and family stress. It was suggested that carers might be forced into paid work leaving siblings in charge. The implications in relation to the costs of housing, transport, and aids and appliances were also identified. In positive terms, the group suggested that governments might respond by implementing more equitable policies. In this respect, they echoed Carroll's (2008) point that it is the official response rather than the economic factors per se that shape their impact and momentum.

Checkpoint reflection

Carroll suggests that there is opportunity for government to invest in both additional services and capital infrastructure.

Can Disability Future Directions make a strong case, combining equity and business interests, to support this investment?

Demographic trends

Drawing from Australian Bureau of Statistics (ABS) data, the Disability Services Commission (2008a) identifies that:

- An estimated total of 405,000 Western Australians (20.6 per cent of the population) have disabilities.
- Of these, 115,900 persons (5.8 per cent of the total population) have profound or severe core activity limitations.
 - 71,600 (61.8 per cent) are under 65 years
 - 44,300 (38.2 per cent) are aged 65 and over.
- It is also emphasised that:
 - Age-specific rates show no significant increases over the five year period 1998-2003
 - The increases in numbers are a result of population increase and population ageing.

(www.disability.wa.gov.au/aboutdisability/disabilityprofile.html)

Charles Duffill (2008), in his monograph on demographic trends, draws on ABS 'Series B' (mid-level) data to estimate (a) population growth, (b) the future numbers of persons with disabilities, (c) the future numbers of persons with profound or severe core activity limitation, and (d) service users. His main findings can be summarised as follows:

Population growth

- The Western Australian population is likely to increase by approximately 21.6 per cent between 2008 and 2023, from 2,102,900 to 2,556,300 persons.
- Most of this increase will be in the population aged 65 and over, which will increase by 83.4 per cent from 263,800 to 483,600 (Duffill 2008: 1-2).

Numbers of persons with disabilities

- Because of the nexus between ageing and disability, the total number of persons with a disability will increase by about 38 per cent over the next 15 years - from 457,000 to a total of 632,600 persons (p.3).
- When those under 65 are considered, the increase of persons with a disability is around 16 per cent, from 309,000 to 359,500. (This increase remains greater than the increase in the corresponding population (12.7 per cent) because some of the age groups in the under 65 year age bracket also have relatively high rates of disability.) (p.3).

Numbers of persons with profound or severe core activity limitation

- The total number of West Australians with profound or severe core activity limitation is projected to increase by about 44 per cent from 132,000 in 2008 to 190,000 in 2023 (p.5)
- There are marked differences between the age groups:

65 years and older	85.2 per cent increase	4.19 per cent annually
45 to 64 years	21.4 per cent increase	1.30 per cent annually
Under 45 years	9.4 per cent increase	0.60 per cent annually

Service users and the pressure on funding

Duffill critiques traditional base-line projections of service user numbers. (These are obtained by setting the expected changes in the reference population against the existing 'service reach' - that is, the proportion of the population currently accessing services.)

The approach, he argues, fails to take into account changes in the rate of demand, driven, in this case, 'not only by the accumulation of unmet demand but also by an expected reduction in the availability of carers' (p.1). Demand pressures over the next 15 years are likely to be socially rather than demographically driven' (p.1).

Duffill (2008: 8) goes on to note that if the traditional baseline projections are employed, the overall increase in persons accessing the Disability Services Commission's (DSC's) services would be in the region of 9.8 per cent over the period between 2008 and 2023. However, if the more pessimistic AIHW (2004) projections concerning the availability of

carers are taken into account,⁴ the rate of demand on Commission services is likely to increase at a much faster rate. Duffill warns:

There are early indications from the Commission's 'Combined Application Process' (CAP) that this might already be happening: In 2001 there were about 5.0 applications per 1,000 persons in the reference population, and in 2005 there were about 6.8 per 1,000. (p. 9)⁵

Funding issues were a prominent item in the interview discussions. In answer to the question concerning the key factors affecting the lives of people with disabilities, their families and carers, funding problems came second together with cost of living. (Social inclusion was ranked first and is considered later in this report.) Some of the comments contained suggestions for change. Thus, for example:

- Families should be able to access at least a minimum amount of support without going into a CAP round. More timely supports reduce the stress on families and builds resilience and coping. Greater collaboration between funding bodies means people wouldn't be confused by the system and wouldn't be disadvantaged by losing some support when they access the others.
- Stability of government funding and financial supports is required to create an environment where both government and non-government sectors can plan ahead effectively and create partnerships to share expertise and resources. Concept of seed funding also supports growth of parent-led organisations, which typically take a long time to grow and develop.

⁴ These indicate a 16% fall in the number of carers in the five year period to 2013.

⁵ During the period, applications increased by over 40%, while the reference population increased by less than 4% (Duffill, 2008: 10). Duffill estimates that the level of unmet demand is twice that of four years ago. This increase is due to the number of new applications consistently exceeding the number of funding allocations per round. In Round 22, there were 70 new applications, but only 37 applications could be funded.

Checkpoint reflection

These considerations point to the need for alternative forms of secure funding. Options, including a Western Australian no-fault, insurance-based, long-term care and/or a national scheme (extending beyond car and workplace accidents), could reduce the pressure on CSTDA funding.⁶

The ageing of the population

The ageing of the population was another important demographic topic, raised in both the interviews and the Think Tank. Unlike some of the more sombre policy deliberations, interview participants thought it had positive as well as negative implications:

- Ageing population presents opportunities: as they age people will increasingly expect to remain connected; transfer of wealth from baby boomers to their children; baby boomers and contribution to revenue from superannuation; the ageing of the population will lead to the growth of the same kinds of services as PWD require.
- People are living longer and will have greater expectations of a full and varied life; complexity of needs will increase and the interfaces between sectors will become more complex. Reduced availability of informal carers. Ageing baby boomers without primary carers.
- Population ageing: implications for workforce participation and workforce shortages; decreased availability of family carers; increase in immigration which in turn will change mix of clients; pressure to make service models less labour intensive; impact on the demand for services and the mix of services available. Increased pressure on budgets.

Mixed conclusions were also reached by Think Tank participants who discussed changes leading to a healthier old age and the role of grandparents, on the one hand, and the

⁶ Examples of innovative community responses considered in the *Community Living Concept Plan* include Keyring and Neighbourhood Networks (UK); Planned Lifetime Advocacy Network PLAN (Canada); Planned Individual Networks (PIN, Western Australia); Person Centred Planning; Microboards (Vela British Columbia and Western Australia); Approaches to Co-Housing (Good Neighbour or Co-Resident).

risks of social isolation, the shortage of carers and pressures to remain in the workforce, on the other.⁷

Checkpoint reflection

In what ways does the ageing of the population present a positive for the community's capacity to care? What new patterns of inter-dependence, stretching beyond the nuclear family, might be encouraged and formed?

Social inequality

Australia is a highly unequal society in which disability is compounded by the divisions attached to socio-economic status, gender, age and ethnicity. The intersecting rather than 'add on' nature of these factors is emphasised. In brief: disability is experienced within and as part of the social and bodily disadvantages/advantages attached to socio-economic status, gender, age and ethnicity rather than 'in addition' to them.

Aboriginal people and disability⁸

In its report, the Disability Sector Health Check Committee (2007) paid particular attention to the issues confronting Aboriginal people. It specifically requested Disability Future Directions to include:

A strong focus on making mainstream services and specialist providers welcoming, accessible and responsive to the needs of Aboriginal people with disabilities and their communities (Recommendation 42).^{9 10}

⁷ The policy implications were also discussed extensively at the meeting between the staff from the policy section of the Disability Services Commission, the authors of the monographs and the research consultant. Here the discussion highlighted the problematic responsibility between Commonwealth and State governments.

⁸ Following Commission practice, the term Aboriginal is used in preference to Indigenous as during statewide consultations, most Aboriginal people preferred to use either the term Aboriginal or the name of their specific language group (see Stopher and D'Antoine, 2008).

⁹ Recommendations 38-43 all concern Aboriginal people.

¹⁰ In 2006 the Commission developed a five-year plan to promote substantive equality. The major work undertaken by the Commission to date includes The *Getting Services Right* information and resource package (2006) and the *Reconciliation Action Plan* (RAP) (2007); funding for an Aboriginal officer to work with agencies to help implement these initiatives; the pilot project at the Mirrabooka LAC office.

In their monograph on Aboriginal disability, Kerry Stopher and Heather D'Antoine (2008) argue that four inter-related factors need to be addressed to achieve effective support for Aboriginal people with disabilities, their families and carers:

- General characteristics of the Aboriginal population
- Characteristics of the policy environment
- Disability characteristics of the Aboriginal population
- Access to disability services.

The crucial findings of their report in relation to the general and disability characteristics of the Aboriginal population include:

- There are significant and enduring differences between Aboriginal and non-Aboriginal people in relation to all the main indicators of health and socio-economic disadvantage. The Council of Australian Government's (COAG) report on Addressing Indigenous Disadvantage (2007) shows that:
 - Life expectancy is around 17 years less for Aboriginal people
 - The unemployment rate for Aboriginal people is about three times the rate for non-Aboriginal people
 - Over half of Aboriginal people receive most of their income from government pensions and allowances
 - Aboriginal people are 13 times more likely than non-Aboriginal people to be imprisoned (cited in Stopher and D'Antoine 2008: 7).
- Around 38 per cent of Aboriginal people aged 15 years and over report having a disability or long-term health condition (ABS 2002). Using criteria similar to that used in the Commission's definition of 'profound or severe core limitation disability', the proportion is around 9 per cent, close to double the corresponding estimates in the total Western Australian population) (p.8).¹¹
- Only 1.5 per cent of Aboriginal people in Western Australia access disability funded or provided services, less than a fifth of those estimated to be eligible (p. 1, 8).

¹¹ Compare this with the Commission's estimate for the total Western Australian population (5.8%). As The Commission's figures include children the difference is likely to be greater given the age profile of the Aboriginal population and the incidence of disability among children and youth.

- Aboriginal people have higher disability rates for all disability types than non-Aboriginal people, the difference being greatest in intellectual disability (four times higher) (p.9).

In relation to access to services (including availability, affordability and acceptability¹²), Stopher and D'Antoine draw attention to the different world view/s of Aboriginal people, in particular the ways in which disability and ill health are understood and supported within the community, comparing them with western notions that position disability as a pathology (p.4). The difficulty non-Aboriginal service providers have in understanding this stands to limit the efficacy and responsiveness of services. Other factors affecting the cultural acceptability and responsiveness of services relate to:

- Service providers' capacity to understand and respond to the fact that disability sits alongside the multiple stressors facing Aboriginal families and cannot be treated in isolation (p.12).
- Cultural sensitivity, including recognition of the enduring legacy of racism (p.12).
- Difficulties in understanding and responding to the issues facing Aboriginal carers (p.13).
- The scarcity of Aboriginal people in the disability workforce (pp.15-16).
- The need for better advocacy services for Aboriginal people (pp. 14-15).

¹² Following the authors' conclusions, primary attention is given to acceptability in the items listed above. Affordability was not in itself found to be a major issue. However, emphasising the fact that the Aboriginal population is more evenly spread across Western Australia than the non-Aboriginal population, Stopher and D'Antoine press the need to improve the availability of specialist disability services in rural and remote areas (p. 5,11)

Checkpoint reflection

A quantum leap?

While acknowledging the policy frameworks in place at national and state levels, Stopher and D'Antoine suggest 'Australia is still in the very early stages of developing effective strategies' and argue that 'quantum leaps are needed' to significantly improve the range of conditions described above. Such improvements would, in turn, bring Aboriginal people onto a level playing field when disability-related issues are addressed in a culturally responsive way. These 'quantum leaps' need to be made 'across jurisdictions, state government agencies and the disability sector and in partnership with the Aboriginal people' (p.17).

How will Disability Future Directions contribute to this?

CaLD populations and disability

In her monograph on the challenges facing people with disabilities from Culturally and Linguistically Diverse (CaLD) backgrounds, Lynne Selepak (2008) notes that Western Australia has a highly diverse population, with a high and rising proportion of people from CaLD backgrounds, including many from new and emerging groups.

- More than a quarter of the population were born overseas, with the state home to people from more than 200 countries (p.1).
- More than 170 different languages are spoken and more than 100 different faiths practised (p.1).
- In 2006 the top five CaLD ancestry groups by birthplace of parent/s were Italy, China, Germany, Holland and India; while the top five language groups (for those who don't speak English at home) were Italian, Mandarin, Cantonese, Vietnamese and Arabic.¹³
- The 10 fastest growing populations from 1996-2001 were Somalia, Sierra Leone, Afghanistan, Oman, Sudan, Iraq, Botswana, Syria, Liberia and Bosnia/Herzegovina (p.2). The numbers of these groups remain relatively small, while their needs are complex and pressing given their past experiences as refugees.

¹³ Selepak notes that neither birthplace nor language alone are reliable indicators of ethnicity.

The monograph identifies a complex of issues facing people with disabilities from CaLD backgrounds including:

- Cultural relevance of services: Many people from CaLD backgrounds may not share western notions of disability and/or may be reluctant to address formal supports.
- Access issues: These include the problems of CaLD populations outside Perth in areas such as Port Hedland/Karratha, the Midwest, Bunbury and the Great Southern, as well as more general language issues (Selepak 2008: 5).
- An accentuation of the difficulties more generally experienced by carers: Studies undertaken by the Ethnic Disability Advocacy Centre (EDAC 2003, 2007) point to considerable cultural and advocacy barriers (Selepak 2008: 6).
- Inadequate data: Selepak observes that the lack of reliable statistics on CaLD disability rates is recognised as an issue by key national organisations including the ABS, the AIHW and the NDEA. The Human Rights and Equal Opportunity Commission (HREOC) (2000) cites this as a major barrier to the effective planning and delivery of services (Selepak 2008: 7).

Checkpoint reflection

Selepak points to the need to respond to 'the complex and pressing needs' of emerging groups, whose numbers may be small but needs urgent, and makes a case for 'strong commitment and strategic action' to ensure that people with disabilities from CaLD backgrounds benefit from services equally with the rest of the population.

How can Disability Future Directions promote this and ensure that members of CaLD populations are involved?

Carers - the work they do

According to the National Survey on Disability, Ageing and Carers (ABS 2004), 13 per cent of people identify as carers. Most primary carers (71 per cent) are female and the majority aged between 45 and 64 years. In her monograph, Selepak (2008) emphasises the enormous contribution they make to the community, providing around 70 per cent of care to people with disabilities. She notes that the imputed value of this unpaid work is estimated to be \$41.4 billion nationally, compared with the estimated \$28.9 billion of total government expenditure on welfare services in 2005-2006 (p. 1).

The multitude of issues facing carers are well documented in the submissions now being made to the House of Representatives Inquiry into Better Support for Carers.¹⁴ Selepak's discussion provides a comprehensive overview of the related literature, drawing our attention to:

Carer health and wellbeing

Research by the National Centre for Social and Economic Modelling (NATSEM) (2006) has found that 59 per cent of all carers report a decline in physical health and two-thirds a decline in mental and emotional health. A survey of carers conducted by Deakin University found carers to have the lowest collective wellbeing index the group had encountered (Cummings et al, 2007; Selepak, 2008: 6-7)

Poverty

The data shows that 'many carers experience poverty and almost all carers face economic challenges' (Selepak 2008:6). NATSEM (2006) found that carers are, on average, \$5,600 worse off each year than non-carers and a government pension is the main source of income for most of them.¹⁵

¹⁴ House of Representatives Standing Committee on Family, Community, Housing and Youth, Inquiry into Better Support for Carers, 2008. Available at: www.aph.gov.au/house/committee/fchy/Carers/subs.htm.

¹⁵ The additional costs of caring for/living with a disability are an important factor here. These are discussed further in this report under 'economic security'.

Workforce participation

Carers of working age have a lower workforce participation rate (39 per cent) than non-carers (68 per cent). Carers who are in or trying to enter the workforce face considerable stress in balancing their dual responsibilities (Selepak 2008: 2, 7)

The lack of services

Selepak (2008: 8) notes the strain the shortfall in community services poses on carers, especially in the areas of accommodation support, respite, alternatives to employment and post-school support. The shortfall places additional stress on carers, with evidence of high levels of unmet need and 'hidden caring' (p. 8).

In relation to future trends, Selepak argues that several factors combine to reinforce 'the need for prompt action to develop additional measures and strategies to support carers' (p.8). These include:

- The ageing of the population
- The fact that people with disabilities are living longer
- An increasing demand for living independently in the community
- The increasing incidence of disability with age
- The fact that more women are entering the workforce.

Many of those interviewed reinforced her points. In the words of one:

For those carers who are getting older there should be support coming into the home to help the parents if it is getting too difficult for them and the person with the disability has not left home. Otherwise it will be too difficult for people to carry on caring.

Selepak (2008: 2) also notes the positive aspects of the caring role: 'It may bring a closer relationship between the carer and the person with a disability, may bring a sense of purpose and personal achievement, and lead to the development of a specialised set of skills and new networks'. Her point is reflected in this participant's vision for the future, a time when:

Caring is seen as a reciprocal relationship with benefits for each party rather than as a burden for one party. The strengths and gifts of each person in the relationship are acknowledged and the role of carer is recognised and valued by the community.

Checkpoint reflection

Selepak urges 'a long term vision and a sustained planning effort' to ensure that carers' needs are adequately met, pointing to the need for coordinated action from all levels of government. How might Disability Future Directions 2025 contribute to this? Does the United Kingdom's Standing Commission on Carers, which aims to make carers central to policy making as equal partners, offer a useful model?

FIVE PRINCIPLES

Introductory

The principles considered here are drawn from the concerns of participants, the Convention on the Rights of Persons with Disabilities, and the Commission's Strategic Plan 2006-2010. They encompass:

- Dignity and respect of person
- Economic security
- Comprehensive access and participation
- Cooperative planning and reciprocal dialogue
- Inclusion.

In discussing them, attention is given to the theoretical significance of each principle, the empirical and policy factors bearing on their realisation in Australia, and the concerns of participants in the interviews and Think Tank. In preface, it is noted that they represent a spectrum of rights, stretching from the most fundamental, in bodily, survival terms, to those more customarily associated with personal actualisation - participation, decision making and inclusion.¹⁶ Paradoxically, the greatest difficulties of realisation appear to lie at the fundamental end of the spectrum, where we find the tough and intractable experiences of day to day care and economic hardship. The importance of responding at all levels of the spectrum, taking day to day hardship as well as the more aspirational goals of community inclusion, was frequently raised in the interviews and at the Think Tank. The response of one of the participants in the interviews provides a timely checkpoint:

¹⁶ This is not to imply they form some kind of hierarchy in the sense inferred by Maslow (body at the bottom, personal actualisation at the apex); simply to make the point that physical and economic security have the most immediate impact on a person's survival. It is in this sense that they are bedrock rights.

Checkpoint reflection

Focus on what people with disabilities want not what looks good on paper. Be visionary but also practical. Remember that quality often lies in the detail... We want this plan to provide us with an instrument for change. PWD are not a homogenous group. Many will need little more than environmental modification to succeed. Others, however, will have major barriers due to the nature of their disability, the level of support they require for even the most ordinary of activity, and their vulnerability to abuse and neglect.

In the brave new world of this plan we want to have something to say and offer to this group of people, their families and carers.

Dignity and respect of person

A guarantee of bodily integrity, including the right to continuity of care, the capacity to make decisions about one's body, physical care, and personal dignity, is a bedrock on which all other principles rest. It includes freedom from abuse, neglect, violence and unwanted medial or technological interventions as well as basic ease in daily living.

Recognising its importance, The Universal Declaration of Human Rights asserts:

'Everyone has the right to life, liberty, and security of person' (Article 3). In parallel, The Convention on the Rights of Persons with Disabilities (the Convention) pays particular attention to rights relating to the 'liberty and security of persons' (Article 14) and 'freedom from abuse, neglect and violence' (Article 16).

Severe or core profound activity limitations, requiring personal assistance or supervision with self care, mobility or communication, render a person physically and emotionally vulnerable. In addition, their capacity to enjoy 'dignity and respect of person' is profoundly affected by the economic and environmental trends considered above. In brief:

- Climate variability threatens fragile lives
- Increases in the cost of living affect physical wellbeing
- Funding restrictions reduce the availability of vital services
- The predicted downturn in carers has consequences for the presence and continuity of care.

The difficulty of finding a solution to these problems was voiced by the interview participant who said:

None of us really have the answers. I would like to see that by the time my son is in his mid twenties he would already be on the path to living somewhere away from home, on his own with people to help him or with other people with disabilities who need help to do things. If that is what people want they should be able to choose it. Wherever people live it should be a safe place.... There should be security and support for people to give whatever help is needed, and to check and make sure that everything is all right.

Issues relating to daily living had a prominent and distinctive place in the Think Tank and interviews. When asked about their vision for people with disabilities, their families and carers in 15 to 20 years time, participants dreamt of an 'ordinary life' in which dignity and respect of person could be assumed.

- Families and individuals have the supports they require to plan and achieve a vision for their lives.
- People with disabilities live where they want, how they want, and with whom they want.
- That people with disabilities and their families will have free choices and the right to choose the level, extent and timeframe that they will provide care.
- That people with disabilities are adequately cared for. That the right services are available at the right time to provide a good life. Holistic support to provide a quality of life. Ongoing planning and assurance that what's needed will be provided. Whole of life planning. A 'normal' life for people with a disability is a given.
- That people with disabilities and their families will have an entitlement to services, not the luck of the draw.
- That families and carers access regular and planned breaks that provide respite designed around individual circumstances; include interim transitional negotiations for changing needs; provide opportunities to investigate futures planning options; and offer the support and continuity necessary to be a valued alternative short-term accommodation option with priority on those with challenging behaviours.

Checkpoint reflection

In the words of one participant: 'Families need to be supported in more positive and protective ways. Protected from dire things which break a family's spirit. Rather focus from early on, on the positive strengths – the good life.'

How to achieve this?

Economic security

Bedrock considerations

In basic terms, economic security involves adequate income, security of housing and the capacity to plan for the future. Incorporated with this, and increasingly vital, is energy security - that is, the capacity to meet energy costs and to enjoy security in heating, cooling, transport and the running of vital equipment. More broadly, economic security involves the capacity to participate in the normal and customary activities of one's society. Over the past half century of related social research, it has been recognised that poverty means marginalisation, isolation and powerlessness as well as financial deprivation.

The Convention establishes the rights of people with disabilities to an 'adequate standard of living and social protection' (Article 28), requiring State Parties to ensure, inter alia:

- The continuous improvement of living conditions
- Access to services appropriate and affordable services
- Assistance from the State with disability-related expenses, including training, counselling, financial assistance and respite care
- Access to public housing programmes
- Equal access by persons with disabilities to retirement benefits and programmes.'

The Australian picture

Based on his comprehensive review of the Australian data, Saunders (2005: 12) concludes:

The presence of disability is associated with low levels of income and high exposure to poverty...The evidence on living conditions paints an even bleaker picture of the impact of disability, revealing large gaps between those with or without it.

[The reason the measures based on living conditions 'paint an even bleaker picture' is that they, unlike the income-based calculations on which the ABS and official Poverty Line estimates rely, take into account the extra expenses faced by households with a disabled member. They reveal the impact that these enforced expenditures have on living conditions including food, holidays, educational costs and recreation. It is to be hoped that the extra costs faced by people with disabilities, as well the inadequacy of pension rates more generally, will be taken into account in the Australian Government's review of the pension system (announced May 2008).]

Drawing from 2003 data, the ABS (2008) reports that families with at least one child with a disability have lower socio-economic status, labour force participation and income when compared with other families with young children aged up to 14 years. They are also more likely to be renting than either owning or paying off their own home. Saunders (2008) notes that in households with a disabled head, poverty continued to rise after the landmark Commission of Inquiry into Poverty (1975), increasing from 20.45 per cent of all households to 26.7 per cent at the last national estimate in 1996 (King, 1998). The situation is unlikely to have improved since then with figures released by the Brotherhood of St Laurence (2007) putting the Disability Support Pension at \$26.70 lower than the poverty line per week.¹⁷

¹⁷ The position is tougher yet for people with disabilities who now rely on Newstart consequent on the reduction in the capacity to work requirement from 30 to 15 hours in the 2006 welfare reforms.

Like physical security, poverty is affected and deepened by the interaction of the trends considered above. In the discussions and at the Think Tank it was noted that the increase in housing prices in Perth and regional centres puts pressure on already stretched resources, and that any scaling down of the public housing sector would force many families to consider private rental with implications for housing design and accessibility as well as cost. It was also pointed out that the increase in oil prices has a disproportionate impact on specialised vehicles and those who need to make frequent visits for medical and paramedical appointments. Economic issues loomed large for interview participants too:

- 'Pricing will become the tipping point for change'.
- Cost of living results in people with disabilities dependent on the family or state, which heightens dependence.
- People with disabilities will face 'the fear and experience of poverty'.
- The interaction of physical and economic factors will put increasing pressure on social cohesion and will test the ethics and compassion for the most vulnerable in society. These global factors will reduce the priority for the less productive members of society, including people with greater levels of disability and their family carers, who will be deemed too expensive and too hopeless to warrant community investment.

By its nature, poverty tends to remain hidden. Further, among welfare theorists there has been a move from a focus on 'redistribution' to 'recognition' - that is, a move from a focus on poverty to a focus on participation. As Williams (2000) acknowledges, the claims of the 'politics of recognition' were long overdue. The problem, rather, lies in the occlusion, or partial occlusion, of the 'politics of redistribution.'

If the politics of recognition characterise our times, what then has happened to the politics of redistribution – of inequalities in income and wealth? The principles of recognition ... have to be seen as part of, not an alternative to, a commitment to meeting people's needs for security, a basic income, employment, health care, housing and education. (Williams, 2000: 1)

Checkpoint reflection

There should be no wait-list and no scrap heap. This means that help and support should be available when it is needed. No one should have to beg for help; and help should not be doled out on a competitive basis where families are competing to be the worst off in order to get some help.

What changes to government policy and practice, and the broader economic context are needed to answer this participant's call?

Comprehensive access and participation

Access issues stand somewhere in the middle of the spectrum of principles. They have long been a key item of disability policy, nationally and internationally. The Convention recognises them both as a General Principle (Article 3) and a stand-alone article. Article 9 states:

To enable persons with disabilities to live independently and participate fully in all aspects of life, State Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communication technologies and systems, and to other facilities and services open or provided to the public.

In the Convention access includes (but is not restricted to): justice (Article 13); information and communication services (Article 21); education (Article 24); health (Article 25); habilitation and rehabilitation (Article 26); and work and employment (Article 27). Accompanying this, Article 29 affirms the right to participate in political and public life while Article 30 affirms the right to participation in cultural life.

The following discussion focuses on (a) the physical environment and (b) employment as two items receiving particular prominence in the interviews and at the Think Tank.

The physical environment¹⁸

Both the interviews and Think Tank acknowledged the importance of the safety and accessibility of the built environment. Participants agreed on the need for 'urban planning to improve proximity to schools, shops, transport,' ensuring a more seamless interface between housing, accessible transport, educational and recreational facilities, and a range of health and welfare services. The ageing of the population was seen to combine with population growth to reinforce the importance of urban friendly environments where people of all ages and physical abilities can live in safety and comfort.

In relation to the future, discussions centred on the impact of the energy crisis. Some participants saw potential for change in so far as it could prompt reinvestment in local areas and less reliance on the car:

- Public opinion will require more planning of how infrastructure such as buildings and public transport achieve sustainability and global standards in use of resources such as power. There needs to be a focus on less private use of cars and an expectation of infrastructure and services for leisure, retail etc in a local area.
- The global energy crisis will initially lead to dislocation and isolation of PWD, their families and carers as fuel and transport become more expensive, with a major impact on the less well off. A second 'localisation' phase will then evolve as the community in general begins to move away from Perth's cultural reliance on cars to access goods, services and recreation on a metro-wide basis, towards a situation where people will expect to shop and recreate in the local area where they live or expect to use improved public transport networks which are available to all.

¹⁸ The *Disability Services Act* (as amended December 1994) requires public authorities to develop and implement Disability Access and Inclusion Plans (DAIPs). These include physical access but are not limited to it, being designed to ensure that people with disabilities:

- have the same access as others to the services, events organised and buildings of a public authority;
- receive information in a way that allows them to access it as readily as others;
- have the same opportunity to be involved in consultations and make complaints.

Others were less sure:

- Will climate warming change people's attitudes and behaviours? Will climate change draw us back to local communities?
- Universal design hasn't come into its own yet. Philosophies of universal design will need to impact on how local government does business, for example, to enable people to stay in their communities.
- Oil crisis is not a temporary blip. Perth is car dependent and this will exacerbate access and hence vulnerability of those with a disability.

Possibilities

Ruth Durack (2008), in her presentation 'Ageing in Place' at a recent Housing and Ageing conference, suggests that 'urban design is a collective enterprise for which we are all responsible and to which we all have something to contribute.' Her reflections on 'elder friendly neighbourhoods' involve:

- Choice: a range of housing types in each area.
- Character: a rich character with diversity of building and landmarks.
- Community events and celebrations.
- Continuity: links to create access of connection.
- Comfort: safe side walks and 'quiet spaces to be alone'.
- Convenience: people able to access most of what they need easily and without using a car.
- Connection: Create beautiful walks and alternative/different options for getting around.
- Community involvement. (Summarised from Durack 2008).

Checkpoint reflection

The energy crisis, population pressure and the ageing of the population present opportunities for imaginative, community centred urban design. Drawing from the principles of universal design, how can these be maximised so that planning is friendly to all its members, including people with disabilities, their families and carers?

Employment

In the discussion between staff from the policy section of the DSC, the authors of the monographs and the research consultant, employment was raised as a pressing and neglected issue. It was emphasised that meaningful employment was pivotal to living a satisfying life for most Australians and should be equally available for people with disabilities. The employment of people with disabilities was identified as a major knowledge gap with more research needed on:

- Different sector opportunities
- Differences between employment practices in the public and private sector
- Commonwealth and State responses and obligations
- The attitudes of employers
- The situation of those facing intersecting patterns of disadvantage
- International developments

Concerns relating to employment filtered through the interviews and the Think Tank's discussion in regard to economic well being and social inclusion. The complexity of the area, and the difficulty of accessing suitable research, hampered these discussions. Accordingly, a brief overview of the situation is offered below.

Labour force participation

A recent report (AIHW 2008) presents a depressing picture of labour force participation rates among adults with disabilities. During the period 1988-2003:

- People with disabilities had persistently lower labour force participation rates than people without disability. Participation rates were about 30 percentage points lower for males and 22-25 percentage points lower for females. For people with severe or profound core limitations, rates were even lower by close to 50 percentage points for males and 40 for females.
- Participation rates for females with non severe or non profound core limitations rose by about 18 percentage points in line with the increase in general female participation rates. The corresponding increase for males was only 6 percentage points. There was no significant increase for either males or females with severe or profound core limitations.

- Almost all the increase in employment for people with disabilities was in the private sector. There was no significant improvement in public sector employment.
- The number of employees with severe or profound core limitations fell in both the private and public sector (AIHW 2008: 3, 22-26).

Employment policy and programs

In February 2008 the Australian Government announced the National Mental Health and Employment Strategy. Its terms of reference state that it 'will outline how policy and programs across portfolios and state, territory and Commonwealth governments can work together to help people with disability and mental illness gain and retain work' (DEEWR 2008a).

Reform is, in fact, long overdue with disability employment programs and policies currently administered across three separate Australian Government Departments.¹⁹

There are also five Commonwealth employment programs for people with disabilities: Disability Employment Network (DEN) - capped and uncapped streams; Vocational Rehabilitation Services (VRS) - capped and uncapped streams; and Supported Employment.²⁰ In addition, there are the state-run day options programs ('Alternatives to Employment in WA').

In making its submission to the Strategy, the Commission (DSC: July 2008b) highlighted the employment needs of people with severe or profound disabilities. Emphasising the value of employment as a means of social inclusion, it urges reforms in overcoming the barriers that make it harder for people to find and keep work, pointing to:

¹⁹The Department of Families and Housing, Community Services and Indigenous Affairs (FaHCSIA) is responsible for administering supported employment services for people with a disability as well as income support policy for people with disabilities and is also responsible for the Commonwealth's broader responsibilities in relation to disability. The Department of Education, Employment and Workplace Relations (DEEWR) is responsible for administering the Disability Employment Network (DEN) and Vocational Rehabilitation Services (VRS), programs which place people with disabilities in open employment. The Australian Government Department of Human Services (DHS) is responsible for administering Centrelink and the Job Capacity Assessors.

²⁰ Formerly known as sheltered workshops and also known as business services, supported employment services for people with a disability have a dual role of both employer and service provider.

- The significance of the school-to-work pathway, given that once people are locked into a state-funded day options program they are unlikely to move from day options to employment.²¹
- The importance of ongoing support for people with severe and profound disabilities who attempt to access employment from tertiary studies, where considerable barriers continue to exist.
- Access to intensive ongoing specialist support and quality employment outcomes for those accessing the labour market from state-funded day options.
- The need for persons employed as Job Capacity Assessors (JCAs)²² to have the skills and training to work with people with severe or profound disabilities.

Earlier in the year (February 2008b), the Department of Education, Employment and Workplace Relations (DEEWR) invited stakeholder submissions on how employment services could be improved.²³ A submission from Western Australian Stakeholders (A Collaborative Response from Western Australian Stakeholders: February 2008) covered staffing and funding issues in detail. It emphasised how the combination of employment and non-employment factors have a significant impact on workforce participation and the need to address these. (Thus, for example, in school to work transition, many families find open employment comprises their capacity to care for their child if the hours and supports are not secure. Day options are then considered more attractive, with the risk

²¹The submission noted that effective models of school to work are operating in South Australia and New South Wales. Promising initiatives in WA include the work undertaken by Edge Employment Solutions (SWEAT).

²² The Job Capacity Assessor (JCA) role was implemented in 2006 as part of the Welfare to Work package. The JCA assesses an individual's work capacity in hours, determining their income support eligibility, and referring them to an employment program. Any person with a disability, including people already receiving DSP, was required to have a Job Capacity Assessment in order to access help to find work. This has acted as a disincentive for people with a disability to volunteer for work for fear of losing their DSP. In response to this the Australian Government announced on 8th September 2008 that DSP recipients would now only require a pre-employment referral assessment to access an employment program. They will no longer be required to have their work capacity and DSP eligibility reviewed.

²³ Drawing on the submissions it had received, in September 2008 DEEWR released a discussion paper titled *Review of Disability Employment Services. Disability Employment Network & Vocational Rehabilitation Services. A Discussion Paper*. The paper identifies three key considerations emerging from the feedback: reduce complexity and red tape; improve flexibility; and the need for better support for vocational education and training.

that the young person may find themselves increasingly locked out of the mainstream workforce.)

The interface between employment and non-employment factors are discussed in a recent report by Cocks and Harvey (2008). Here they draw on extensive interview data to reveal:

- Families' preferences for a 'stable option'
- The fact that open employment is often seen as 'high risk' with a lack of safety nets
- The lack of interface and pathways between employment services
- Funding limitations
- A service system of silos restricting and confusing opportunities
- Clients' concern over job capacity assessments

The comments from the interview data are instructive. Thus, for example:

If your son or daughter requires a reasonably high level intervention, you might say to yourself it'd be a better option to pump for a state-run day options program that might get us 25 hours a week than to risk open employment that might get us eight...That's a real barrier. Equally, (you might opt for) a promise of 26 hours a week or more in a business service as opposed to eight hours a week in open employment, given that many of the business services are also connected to broader whole of life support structures...

There's a problem around having to resign if you wanted to try moving from a business service into open employment. There would be enormous fear for parents of jeopardising a business service place. Especially for ageing parents. They are not going to take the risk of a move to open employment.

...the level of funding goes nowhere near being able to support anything more than an 8-10 hour week job for someone with high support needs...

Checkpoint reflection

What changes in labour force culture are needed to make open work welcoming and accommodating to all its members, current and potential?

How would we go about obtaining this information?

Cooperative planning and reciprocal dialogue

In its preamble, the Convention recognises that:

Persons with disabilities should have the opportunity to be actively involved in decision making processes about policies and programmes, including those that directly affect them.

The principle of 'nothing about us, without us' was strongly voiced in the interviews and reinforced many times over in the Think Tank. It is well reflected in the Commission's consultative processes and the composition of its Board.²⁴

There are, however, limitations to the 'decision making' approach. In essence, it can limit participation to:

- involving individuals and communities in consultations while making decisions in another forum, distant from them; and/or
- involving key representatives of disability groups in decision making while restricting discussion to those sites, distant from the everyday lives of ordinary people.

In both cases, policymaking tends to follow a linear, goal-oriented pattern:

discussion ⇒ planning ⇒ decision ⇒ action. While there are strategic merits to this, there are limitations: namely, the failure to 'stay close to the ground' and to continually reflect on changing conditions.

The possibility and importance of doing things differently was well articulated in the Think Tank - where one participant directly raised the possibility of the 'kitchen table' discussions mentioned below - and the importance of 'conversation' was affirmed in the

²⁴ The Commission's Board of nine members has at least five members either with a disability, a relative with a disability or recent experience as a carer or advocate.

concluding address. It was also prominent in the interviews. Question 5 asked participants: 'What is the most important thing you would like to tell people who are developing future directions for disability?' It is instructive that the highest priority was given to listening, participation and trust:

- Talk with families. It's not rocket science to see what's needed.
- Listen to what PWD and carers of PWD have to say – don't do anything about us without us.
- PWD are the most knowledgeable about the issues and agendas that have the greatest impact on their daily lives. For too long disability services agendas have been the agendas of decision makers and not that of the PWD's ideas, agendas and issues.
- Keep in touch with people and use their stories as levers to identify solutions. Be strategic and structured in planning with a long term outlook. Undertake good research. Be solutions focused. Ensure regular review.
- Listen to PWD, their families and carers and the NGO sector that services/supports them. Consultation fatigue is for real.
- Focus on what PWD and their families want, not what looks good on paper. Be visionary but also practical. Remember that quality often lies in the detail for PWD. We want this plan to provide us with an instrument of change.

Checkpoint reflection

It may not be rocket science, but involving people as they go about their everyday lives in the ongoing development of Disability Future Directions might well be revolutionary. How can policy respond to kitchen table conversations? Can we learn from yarning sessions? How can the asymmetries of power and influence be addressed? What does the international experience tell us?

Inclusion

Inclusion is rather different from the principles considered so far in that it stands as an encompassing vision, a philosophy, with implications across all domains, rather than marking out a particular course of action or set of programs. The Commission's vision expresses this well, looking to a future where:

All people live in welcoming communities which facilitate citizenship, friendship, mutual support and a fair go for everyone.

In the Convention, inclusion is upheld both as a general principle and a general obligation.

Article 3 affirms:

- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.

Article 4 places on State Parties the obligation to:

Ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.

Full inclusion in the community was the first priority of participants in the Think Tank and interviews. When asked about their aspirations for the future, interview participants put community inclusion as their first priority; when questioned about their concerns, they raised community discrimination.

Aspirations for the future

The desired future was one when people with disabilities are totally included and welcomed in mainstream community life and their value and strengths recognised.

- That people with a disability live lives that are indistinguishable from those around them. That there is a ready, easy acceptance of people with disabilities in every aspect of life.
- People with disabilities are valued and contributing members of the community, not a marginalised or 'special' group that requires 'specialised responses'.
- People with a disability will be engaged and embedded in their local community. They WILL make a meaningful contribution; WILL have relationships and friends. WILL make their own choices about big and small issues/decisions in their lives.
- That people with disabilities are afforded full citizenship. Citizenship is the ultimate measure. It's what we all want and incorporates participating, giving and receiving. Doesn't focus on inclusion/exclusion.
- Acceptance and understanding – all Australians will have a positive attitude towards disability that focuses on the abilities. People with disabilities are involved in every fibre of society. The government and people recognise, respect and value the work of carers and all service providers, not only for people with disabilities but all those who provide a service in the wide Australian community.

Concerns

The challenge to inclusion was seen to lie in community attitudes.²⁵ Here participants reflected on the nature of difference and how people respond to this.

- Society's fears – fears generally and fear of people with disabilities which affects how they are treated. A narrow view of 'normal' which might get a little better by 2025, but restricts how people see others and how willing to help and accept.
- If we continue to see people with disabilities as separate and different we run the risk of perpetuating stereotypes and exclusion. We must be cautious of requesting disability specific responses.
- A lack of understanding about difference. Don't think this is going to get better. If we're serious about inclusion we need a massive education campaign about the inclusion of differences. Joint responsibility – not just of the community but also of PWD and their families

They also touched on individualism and insularity:

- Society too individualist in thinking and not considering the needs of vulnerable and people without skills and strength to have a voice. Society too money-centred, self-gratification.
- Y Gens versus baby boomers – lack of responsibility by Y Gens.
- Our society is becoming more insular. People are spending less time out and about in their community and more time in their own home, for example, working from home, less involvement in community activities – we are less connected.

Overall, however, participants were optimistic, looking to community education and the effect of the increasing public presence of people with disabilities.

²⁵ These are further discussed under 'Change: Possibilities and Barriers' below.

- Opportunities to show off the abilities and talents of people living with disability will positively influence attitudes towards the contribution of PWD to society. Diversity within any society provides constant opportunities for conflict but the way this plays out is influenced by the larger national or global context (attitudes to 'us' and 'them' will therefore change over time). Positive discrimination would be one way to kick start this process.
- Generation Y provides an opportunity for greater community acceptance of PWD. Siblings who have grown up at home with their sibling with disabilities. Kids who have kids with disabilities in the mainstream classroom.
- Society will become more inclusive due to a greater presence of PWD in people's lives eg kids with disabilities in mainstream school. (A possible counter trend might be the smartness and savvy that is valued by Gen Y which might not include some people with disabilities. People's perceptions are shaped by familiarity.) Need opportunities for people to identify the person in people with disabilities to find a point of commonality. See SCOPE UK campaign.
- The more people with disabilities 'emerge' the more that acceptance will improve.

Checkpoint reflection

One participant notes: 'a focus on inclusive communities and celebrating diversity needs real leadership to get beyond the initial reaction of rejection, alienation, difference and the 'other' to be scape-goated.'

Another urges; 'If we're serious about inclusion we need a massive education campaign about the inclusion of differences. Joint responsibility – not just of the community but also of PWD and their families.'

How should Disability Future Directions respond?

CHANGE: POSSIBILITIES AND BARRIERS

Historical and contemporary trends

In her monograph on national and international trends, Samantha Jenkinson (2008) traces the changes that have occurred over time, drawing attention to:

- The move from institutionalisation and segregation to de-institutionalisation and community living;
- Changes in the definition and understanding of disability: from the medical to the social model;
- Changes in the underlying ideological positions: from pathology to social role valorisation (SRV), and from SRV to disability rights and independent living.

She suggests that while Australia has seen a policy shift 'toward individualised or person-centred approaches', there yet remain many services and programs, here and internationally, 'still working in institutional or medical models or somewhere in between'. She attributes this to a 'concern for the level of risk and need for safeguards' which can 'swing the balance back to inflexible and restrictive responses' (p. 7-8).

In relation to the problematic factors impacting on current and future developments Jenkinson (2008) considers:

- Isolation and segregation: The closing of large institutions and the move to group homes will not herald the end to institutionalisation without adequate supports for inclusion, participation and self-determination (pp. 17-18).
- Organisational culture: To secure a genuine shift to inclusion, we need to change more than the language and 'bring everyone along with the change' (pp. 18-19).
- Workforce issues: The lack of support staff, inflexibilities in taxation and compensation rules, and lack of training and career possibilities reduce the capacities of the disability services sector (p. 19).
- Fragmentation: Funding is fragmented into 'discrete buckets' with separate eligibility criteria (day care options, accommodation options, community access) undermining the notion of community access. In addition, the Commonwealth State Territory

Disability Agreement (CSTDA) categories of funding and the Commonwealth / State separation of responsibilities 'maintain a fractured system' (p. 20).²⁶

- Lack of resources and competition for services: Official definitions determine who is eligible, sometimes with perverse results; there are few services and little choice in rural and remote areas (p. 21).

Checkpoint reflection

At a number of points in her monograph, Jenkinson pushes the need for organisational and political change – changes that go beyond language, walk the talk, and make inclusionist and person centred philosophies a reality.

How can Disability Future Directions meet her challenge both in its own operations and advancing change more generally?

Participants' views of change

In the interviews participants were asked two questions on the negative forces affecting change:

- What things might stand in the way of your vision becoming a reality? (Question 5)
- What are your fears or concerns for people with disabilities, their families and carers over the next 15-20 years? (Question 6)

There was considerable overlap between the answers to these questions, which may therefore be usefully considered together. The responses can be grouped under three themes:

- 'Bureaucracy too far away'
- The issues facing families and the impact of funding restrictions
- Attitudes to disability leading to isolation and segregation

²⁶ Following the Council of Australian Governments' (COAG's) meeting in January 2008 the CSTDA is currently under review as one of the 90 Specific Purpose Payments (SPP) - that is, grants allocated the states for designated purposes. It will be replaced by a new disability SSP and may be accompanied by a National Partnership Payment (NPP).

Bureaucracy too far away

A number of participants (14) voiced their fear that there would be no change. This was related to the 'bureaucracy too far away' theme which centred on (a) entrenched views and vested interests, and (b) red tape and over regulation, including top down policy development.

Entrenched views and vested interests

- Entrenched views – who has the most to gain or lose by change? Who has the most power?
- Vested interests – maintaining silos, empire building, increased bureaucracy and complexity.
- Egos and ulterior motives – State versus Commonwealth blame shifting culture and reluctance to acknowledge the depth of the issues and this then means they will need to fund solutions.
- Change too radical and too threatening to existing power structures.
- Politics of the disability sector – kingdoms.

Red tape and over regulation

- Too much red tape and bureaucracy.
- Bureaucratic way of thinking. More people in bureaucratic roles and less people doing the hands on work.
- Policy changes that will increase red tape and make life harder.
- Over regulation. Over compliance. Cost of bureaucracy. Conflict between State and Commonwealth, Conflict age versus disability. Poor governance. Red tape. Government short term vision.
- Derogatory Government policies – that is top down imposition of decisions without consultation with individuals and their families and carers.

The issues facing families and the impact of funding restrictions

In talking about their greatest fears for the future, many participants talked about the marginalisation and isolation of families and their sequelae in terms of loneliness and potential abuse.

- Families become increasingly marginalised and the risks of abuse increase.
- Who will care for my son when I'm no longer able to cope?
- That adequate support will not be available to enable people with disabilities to live safely in the community thereby increasing their vulnerability.
- Family isolation and continued suffering behind closed doors due to huge burden of care.
- It will continue to be the women who care, who continue to age in poverty because they are left with the caring role.
- That the needs of Indigenous families will be misunderstood, poorly planned and inappropriately funded.

Particular attention was given to families at the toughest end of the spectrum:²⁷

- Fear that people with disabilities with health and mental issues will be neglected.
- A lot of good things will happen for most people with disabilities, but concerned that some with more profound disabilities will not fit into this 'bright new world'. Fear is that government won't commit to safeguard the minority with the greatest needs.
- Availability of funding for people with complex care needs who require specialised services.
- That planning and emphasis is not given to those whose needs are less complex and demanding than those individuals at the severe end of the spectrum who are reliant on their families and society to meet all of their needs.

²⁷ These comments highlight a range of *intractable issues*. There are people who face difficulties the rest of society can barely comprehend; difficulties of pain, tiredness, grief and loss that won't go away. The aspirational language of government and other public documents shies away from the intractable and, in so doing, may invalidate the experiences of those who suffer from them. A new way of respecting and acknowledging the experiences, along with the limitations of government, is important.

Inequity and competition for funds was closely allied to these concerns, as they impacted on the capacity of services to respond. Here participants talked about:

- Lack of equity across the sector.
- Competing demands and priorities.
- Competition and waiting time for assistance will become intolerable. Extent and content of assistance once it has been acquired will be very limited. Limitations on services and enduring options will contribute to family stress and breakdown.
- The sense that it is too hard in rural and remote areas and therefore less than the best is OK
- That the disability community will fracture eg between intellectual disability and non-intellectual disability, or between carers and people with disabilities

Community attitudes to disability

Inclusion is a good idea but the reality is different. It requires a shift of mindset.

Many others agreed with this participant's observation, mentioning labelling, social stereotypes and community indifference. Negative attitudes were seen to have multiple causes including:

- Media portrayal of people with disabilities as a burden, threat, non contributors, user of resources, dependent, helpless.
- The notion of carer has permeated the field of human service provision bringing with it perceptions of custodial models and lowered expectations or awareness for the capacities of people with an intellectual disability.
- On one hand we have increased the visibility of people with a disability and we have increased the expectations of families and individuals for their lives, but we aren't accommodating these.
- Disability issues and the ageing of carers are seen as an 'old' topic – not something new to interest the general public. If people aren't kept aware of these issues it makes it more difficult for people with disabilities, their families and carers. Awareness does make a difference.

Negative community attitudes lead to the isolation and segregation of people with disabilities, with particularly profound implications for ethnic minorities and those with the highest support needs:

- People from ethnic backgrounds with a disability are at greater risk of isolation and lack of support as they are often doubly vulnerable because they are frequently marginalised and isolated from their own communities because of community attitudes to disability.
- Certain groups of people, with disabilities and caring for them, will become more disadvantaged and isolated.
- Those with the highest support needs will become marginalised at edge of society physically and socially.
- Disability morphing into a sub class of 'others'. Not considered part of society but are considered to need specialised responses outside of the general mode of delivery.

Building on strength

The countervailing force, however, was the strength of individuals and families themselves:

- PWD are not heroes or victims but agents of their own destiny.
- Put PWD in control, in the driver's seat.
- Directly provide the resources that a person needs and develop models that facilitate where individual choice is a factor.
- The most important thing to remember is to take care of the whole person with a disability. For example, think about their education and their health and help families to plan for the future.
- Make the service fit the person rather than the other way around.

WORKING AT THE INTERFACE

Setting priorities

How to proceed? It is suggested that advantage be taken of the broad ranging nature of Stage One discussions by adopting an encompassing yet detailed approach to the Commission's Vision, spelling out and advancing the economic, social and environmental elements necessary to achieve 'a society in which all people live in welcoming communities which facilitate citizenship, friendship, mutual support and a fair go for everyone.' It is also proposed that this is best undertaken by 'working at the interface' – that is, working at that point where the underlying trends impact directly on the lives of people with disabilities, their families and carers.

On the one side of this interface are global, national and international trends over which the Commission has little or no control. On the other, is the internal work of the Commission, the day to day business of service planning and delivery. To concentrate solely on the underlying trends is unrealistic (the Commission cannot affect climate change, inflation or the historic factors underlying social inequality); to stay purely within established frameworks is to lose the opportunity to work with key players to shape the economic, social and physical environment to the advantage of all the members of our society.

The following tables - separately relating to the economic, social and physical environments - set out, in summary form, what 'working at the interface' might entail.

Each indicates:

- The main trends. Although separated for analytical and pragmatic purposes, the trends combine and intersect to provide a far more complex picture than allowed for in the tables.
- The suggested priorities for Disability Future Directions. These are drawn from the monographs, interviews and five principles. Again the situation is messier and more complex than a mere table can allow: the priorities are affected by the intersection of trends and their realisation is interdependent.

- The main players and the auspice of responsibility. The nominated players are indicative only and will need further consideration and broadening out as discussion proceeds. It is emphasised that dialogue with people with disabilities, their families and carers should underpin the development of all the nominated priorities: the final column refers only to the bodies that are responsible/accountable.

Notes

- i. This mapping is broad brush. The implications would need fleshing out through separate discussions relating to:
 - Different disability types: intellectual, neurological, sensory, physical
 - Different life stages: early childhood, school, school to work transition, working age, seniors
 - The particular issues and challenges facing Aboriginal people
 - The particular issues and challenges facing minority CaLD populations
 - The circumstances of carers.
- ii. Although it is important that the differences within the disability population are thus recognised and highlighted, it is equally important that the framework does not become splintered into a maze of fragmented and competing priorities. The approach needs to keep the Commission's vision in mind - that is, all people should enjoy more equitable economic conditions, a friendly community and a hospitable physical environment.
- iii. Separate discussions also need to be held relating to the institutional context of this framework with particular reference to workforce planning²⁸ and intergovernmental relations.

²⁸ In the 2006-2007 Annual Report the then Assistant Director General concluded that:
A significant emerging issue for the Commission and the wider disability services sector is workforce sustainability. The vibrant economy and competitiveness within the human services sector are making it increasingly difficult for the Commission and our non-government agency partners to maintain the staff they need to provide needed services. This will continue to be a major challenge for the sector in the years ahead and a high level of creativity will be required to ensure that our services continue to attract the high calibre people we need to support people with disabilities to lead good lives in the Western Australian community (Disability Services Commission 2007b: 3).

A more equitable economic environment

Trends over the next 15 to 20 years	Priorities	Main players and auspice of responsibility
Many families continue to live around or below the poverty line because of cost of living pressures, including food, energy and transport	<p>Economic security for people with disabilities, their families and carers</p> <p>Energy security for people with disabilities, their families and carers</p>	Commonwealth (pension levels); State Government; Synergy; Alinta; Transperth; the Commission.
Housing prices and pressures	<p>Housing security and safe environments for people with disabilities, their families and carers</p> <p>Addressing housing choice and diversity, with special attention to location, density, varieties of housing stock, and affordability</p>	State Government; Department of Planning and Infrastructure; Homeswest; local government; Real Estate Institute of Western Australia.
Labour force participation rates do not yet show benefits for people with disabilities	Improvement of workforce opportunities, particularly for those with profound or severe core activity limitations	Public and private sector employers; service providers; the Commission; State Government; Commonwealth Government: National Mental Health and Employment Strategy; FaHCSIA; DEEWR; DHS.
Funding shortfall in services, exacerbated by demographic change and increasing rate of demand	Guarantee of flexible and appropriate services for all people with disabilities, their families and carers	CSTDA; NDS; Service providers; Community Living Plan.
Continuing differences between metropolitan, regional and rural remote Australia	Reduction of disparities, particularly in specialist services	State Government Planning Commission (WAPC); State Government; the Commission.

A friendly social environment

Trends over the next 15 to 20 years	Priorities	Main players and auspice of responsibility
Inequalities of age, gender, ethnicity, socio-economic status and geographical location intersect with and compound disability	<p>Addressing disability and all other areas of social and economic disadvantage, including health, education, employment and justice, with Aboriginal people in a serious, cooperative and sustained manner</p> <p>Greater cultural diversity and sensitivity in the planning and delivery of services with particular attention to the urgent and complex needs of emergent CaLD groups</p>	<p>State and Commonwealth Government; public sector; business corporations; Aboriginal communities and organisations; service providers.</p> <p>CaLD communities and organisations; service providers.</p>
Ageing of the population with implications for pressure on services, availability of carers, and the profile and prevalence of disability	More effective and responsive interface between formal and informal care and between aged care and disability sectors	CSTDA; FaCHSIA; NDS; disability and mainstream service providers; the Commission; the Community Living Plan.
Carers, who provide 70 per cent of the care for people with disabilities, face considerable economic, social and health issues. The numbers of those willing and able to provide intensive care likely to fall	<p>Significant improvement in the economic and social circumstances of carers</p> <p>Effective interface between formal and informal care</p>	Carer organisations; Commonwealth Government (pension levels); NDS; service providers.
Within the sector a move toward independent living with continued need for residential and respite care	Ensuring respect and dignity of person in daily living in all contexts.	Disability service providers; NDS

A mixed environment in relation to the genuine acceptance and valuing of people with disabilities	A sustained move to a genuinely inclusive society that values and respects difference	Schools; workplaces; clubs; churches; media, advertising; local and state governments; NDS; the Commission.
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A hospitable physical environment

Trends over the next 15 to 20 years	Priorities	Main players and auspice of responsibility
Climate variability with implications for environmental sustainability, food production, physical, economic and housing security	Safeguarding the physical, social and economic security of people with disabilities, their families and carers.	State Government; public health; Synergy; Homeswest; Alinta; Water Corporation; telecommunications.
Changes to urban design and transport consequent on the energy/oil crisis	Ensuring safe and friendly environments for people with disabilities at all ages	DPI; urban planning institutes; Transperth; DAIPs.

Ideas to date

During the discussions to date many ideas have surfaced in relation to progressing these initiatives. Further consideration of these and additional ideas will occur as Disability Future Directions 2025 is developed. The ideas range widely from promoting significant taxation reform, to ensuring solar and fuel energy rebates extend to people who are economically vulnerable; from influencing the design and access of local communities where more people are likely to spend more of their time, to developing strategies to safeguard the quality of life for people without a strong community voice - those who live in supported accommodation where workforce, fuel, energy and other cost-of-living pressures will also bear increasing impact.

Conversations for change

As indicated above, the development of Disability Future Directions over time will involve multi-layered conversations with a variety of players, including individuals and families; communities; service providers; government agencies; and the corporate sector. Three characteristics of these 'conversations' are noted:

- i. The particular purpose, content and power relations of each will vary. Discussions with the ABS, for example, provide technical data; those with families and communities, experiential information. In the one case, the Commission is client, in the other service provider. Such considerations affect the nature and timing of the conversations, how often they take place; and where they are located - desks or kitchen tables.
- ii. A conversation, to be a conversation, needs to be an open exchange of views and ideas not an exchange where one party has invisibly set the agenda and parameters. Ironically, this may involve government revealing its limitations as much as its vision and potential.
- iii. Such conversations need to proceed over the years, constituting an ongoing dialogue about emerging trends and the developments needed to promote economic equity, friendly communities and hospitable physical environments.

Although the economic, social and environmental priorities identified here are disability focused, they relate to universal rights rather than special needs. While disability has been one of the last to emerge in relation to affirmative action and equality of opportunity - well preceded by gender and ethnicity - it has particularly significant implications as far as the 'good society' is concerned. Its emphasis on universal design, on broad spectrum responses friendly to all people at all ages and stages, has a transformative potential. In this sense, Disability Future Directions 2025 is about the economic, social and environmental fabric of Western Australian society as a whole.

REFERENCES

Australian Bureau of Statistics (2002) *National Aboriginal and Torres Strait Islander Social Survey*, Australian Bureau of Statistics, Canberra.

Australian Bureau of Statistics (2004) *Disability, Ageing and Carers, Australia: Summary of Findings*, Australian Bureau of Statistics, Canberra.

Australian Bureau of Statistics (2008) *Families with Young Child with a Disability, Social Trends*, Australian Bureau of Statistics, Canberra.

Australian Institute of Health and Welfare (2004) *Carers in Australia*. AIHW, Canberra.

Australian Institute of Health and Welfare (2008) 'Disability in Australia, trends in prevalence, education, employment and community living'. *Bulletin 61*, Australian Institute of Health and Welfare, Canberra.

Brotherhood of St Laurence (2007) *Poverty Line Update*. Available at:

www.bsl.org.au/pdfs/poverty-line-update/Aug2007/pdf

Carroll, M 'Economic trends: introductory comments', Work in progress, *Trends*, Disability Services Commission, Perth, Western Australia.

Cocks, E and Harvey, T (2008) *Employment-day Options Interface Research Project – Draft Final Report* (Unpublished), commissioned by the Disability Policy Research Working Group, Disability Services Commission, Perth, Western Australia.

Collaborative Response from Western Australian Stakeholders (February 2008) *Improving Employment Services in 2009*, Submission to Department of Employment Education and Workplace Relations, Perth, Western Australia.

Commission of Inquiry into Poverty (1975) *Poverty in Australia*, Australian Government Publishing Service, Canberra.

Community Living Concept Plan (August 2008) *Stage One Report*, Disability Services Commission, Perth, Western Australia.

Council of Australian Governments (2007) *Addressing Indigenous Disadvantage: Key Indicators 2007*. Steering Committee for the Review of Government Service Provision, Canberra.

Cummings, R Hughes, J et al (2007) *Report of the Australian Unity Wellbeing Index Survey*, Deakin University, Victoria.

Department of Employment Education and Workplace Relations (2008a) *National Mental Health and Disability Employment Strategy – Terms of Reference*, Department of Employment Education and Workplace Relations, Canberra.

Department of Employment Education and Workplace Relations (2008b) *Review of Disability Employment Services. Disability Employment Network & Vocational Rehabilitation Services*. A Discussion Paper, Department of Employment Education and Workplace Relations, Canberra.

Disability Health Sector Check Committee Report (2007) Executive Summary, Available at www.disability.wa.gov.au.

Disability Services Commission (2006) Disability Services Commission *Strategic Plan 2006 to 2010*, Disability Services Commission, Perth.

Disability Services Commission (2007a) *Reconciliation Action Plan*, Disability Services Commission, Perth, Western Australia.

Disability Services Commission (2007b) *Annual Report 2006-2007*, Disability Services Commission, Perth, Western Australia.

Disability Services Commission (2008a) 'About disability: disability profile' www.disability.wa.gov.au/aboutdisability/disabilityprofile.html

Disability Services Commission (2008b) *National Mental Health & Disability Employment Strategy: Submission by the Western Australian Disability Services Commission*, Disability Services Commission, Perth.

Duffill, C (2008) *Demographic Trends*, Disability Services Commission, Perth, Western Australia.

Durack, R (2008) 'Ageing in place', Paper given at the Ageing and Housing Seminar, Perth, Western Australia.

Ethnic Disability Advocacy Centre (2003) *Supporting CaLD Carers: The Service Needs of Culturally and Linguistically Diverse Carers of People with Disabilities*, Ethnic Disability Advocacy Centre, Perth, Western Australia. Available at:

<http://www.edac.org.au/rescarers03.pdf>.

Ethnic Disability Advocacy Centre and Carers (2007), *Speak Up*, Ethnic Disability Advocacy Centre, Perth, Western Australia. Available at:

www.edac.org.au/1208soeak.pdf.

Human Rights and Equal Opportunity Commission (2000) *On the Sidelines - Disability and People from Non English Speaking Backgrounds*, Human Rights and Equal Opportunity Commission, Sydney, New South Wales.

Intergovernmental Panel on Climate Change (2007) *Fourth Assessment Report*, Watson, RT and the Core Writing Team (eds) Intergovernmental Panel on Climate Change, Geneva, Switzerland.

Jenkinson, S (2008) *Local, National and International Trends*, Disability Services Commission, Perth, Western Australia.

King, A (1998) 'Income Poverty since the 1970s', in R Fincher and J Niewenhuysen (eds) *Australian Poverty, Then and Now*, Melbourne University Press, Melbourne, pp 71-102.

National Centre for Social and Economic Modelling (2006) *The Cost of Caring in Australia, 2202 to 20025, Who cares?* National Centre for Social and Economic Modelling, Canberra.

Saunders, P (2005) *Disability, Poverty and Living Standards: Reviewing the Australian Evidence and Politics*, Social Welfare Research Centre, University of New South Wales, Sydney.

Selepak, L (2008) *Carers*, Disability Services Commission, Perth, Western Australia.

Selepak, L (2008) *Challenges Facing People with Disabilities from CaLD Backgrounds*, Disability Services Commission, Perth, Western Australia.

Shakespeare, T (2006) *Disability Rights and Wrongs*, Routledge, London.

Shakespeare, T (2007) 'Disability rights'. Available at: www.watch.net/article/disability

Spickett, J, Brown, H and Katsherian D (2008) *Health Impacts of Climate Change: Adaption Strategies for Western Australia*, Department of Health, Perth, Western Australia.

Stehlik, D and Costello, D (2008) *Climate Variability and Social Vulnerability: A Brief Statement of the Issues*, Alcoa Research Centre for Stronger Communities, Curtin University of Technology, Western Australia.

Stern, N (2007) *Economics of Climate Change: The Stern Review*, Cambridge University Press, Cambridge.

Stopher, K and D'Antoine, H (2008) *Aboriginal Disability*, Disability Services Commission, Perth, Western Australia.

United Nations (1948) *The Universal Declaration of Human Rights*. Available at: <http://www.un.org/Overview/rights.html>.

United Nations (2006) *Convention on the Rights of Persons with Disabilities*, convopt-e 20-18-00-pdf.

Williams, F (2000), Inaugural lecture as Professor of Social Policy, Director, ESRC Research Group for the Study of Care, Values and the Future of Welfare. *Travels with Nanny, Destination Good Enough. A Personal Intellectual Journey through the Welfare State*. Fiona Williams, Professorial Inaugural Lecture. 20May.webarchive.