

DISABILITY FUTURE DIRECTIONS 2025

Heading in Helpful Directions

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DISABILITY FUTURE DIRECTIONS – 2025

HEADING IN HELPFUL DIRECTIONS

INTRODUCTORY

This paper is the outcome of a meeting between staff from the policy section of the Disability Services Commission, the authors of the Disability Future Directions 2025 monographs and the research consultant. It sets out a number of issues the Disability Future Directions 2025 Reference Group may wish to consider. Its title reflects participants' belief that:

- There is no single 'right' way for the future to unfold for people with disabilities, their families and carers.
- There are, nevertheless, more or less 'helpful' directions - that is, directions that are more or less likely to make a genuine difference and be both practical and imaginative.

In this context, participants' considerations point to the importance of three underlying factors:

- Framing
- Listening
- Acting.

A number of pressing issues were also considered - matters that need to be taken into account by Disability Future Directions 2025. These are considered at the end of the paper.

FRAMING

The terms in which an issue is framed determine the policy directions taken. If, for example, disability is seen as a matter of personal disadvantage, the directions will be very different than if it is conceptualised as a matter of

public responsibility. The foundational assumptions associated with framing often remain unarticulated and unquestioned as they reflect the way things are seen and understood at the time. Bringing them out of the shadows is vital for they determine the nature and effectiveness of both policy and strategy.

In the case of Disability Future Directions 2025 this may be particularly important given the shifts that have taken place over time - thus the move, or partial move, from institutionalisation to deinstitutionalisation, from social role valorisation to a human rights approach, and from the language of 'needs' to 'social inclusion'. If the new process is not to be seen as 'just the next thing', the thinking behind it and its implications for effective and helpful change need to be made clear.

In this context, participants' concerns related to:

- Current framings of the notion of disability
- The language surrounding eligibility
- The relationship between rhetoric and practice
- The tendency for disability to fall below the radar of public and political attention.

Current framings of the notion of disability

It was suggested that in Australia disability is predominantly cast as:

- A lack, deficiency or disadvantage.¹ This deflects attention from the structural factors that produce inequality and disadvantage.
- A natural phenomenon, which, because it is not perceived to arise from political action, does not carry the same burden of responsibility or

¹ It was noted that funding is dependent on demonstrating need.

guilt and the consequent requirement to act, now attached to the inequalities arising from gender, race and ethnicity.

- A medical condition, which even if natural, can and should be treated or normalised.

It was noted that the notion of disability as deficiency and/or abnormality has significant cultural implications. As reported in the monograph on Aboriginal people with disabilities, Indigenous people have spoken of its potential to devalue those with disabilities and of its dissonance from their own worldview. The same was said to be true of some CaLD populations.

These notions can be contrasted with The International Classification of Functioning, Disability and Health (ICF), the WHO's framework for measuring health and disability at both individual and population levels. The ICF mainstreams the notion of disability by acknowledging that most humans will experience some degree of impairment during their lives. It concentrates on the 'disabling' impact of the environment - that is, on those physical, social and/or cultural factors that limit a person's functioning. Under it, people have 'impairments'; it is the environment that 'disables'. It is a rights-based model with the onus on policy makers to ensure that persons with impairments enjoy the same quality of life as everyone else.

The approach is currently promoted by the AIHW as an alternative to the medical model. Further, as a signatory to the UN Convention on the Rights of Persons with Disabilities, Australia is now well placed to participate in the development of a common, international "human rights" approach.

The language surrounding eligibility

It was argued that the framing of eligibility provisions in Australia places the burden on the applicant to demonstrate eligibility thus assuming ineligibility unless the counter case can be made. Designed to restrict and ration access, this operates in contrast to the ethos of social inclusion. It also contrasts strongly with a human rights approach. In this and other contexts, participants noted the need for organisational and cultural change.

The relationship between rhetoric and practice

Three main factors were discussed:

- i. The gap between policy rhetoric and the provision of services. By way of example participants queried how far the discourse of 'person centred' approaches translates into actual practice. How many people with disabilities and their carers are really receiving this kind of service?
- ii. The values and language used in the training of some disability sector workers. Current thinking is not necessarily reflected in the training of workers, which may reflect the traditions and values of older models.
- iii. The need for policy discourse to be practicable - that is, grounded in the everyday experiences, expectations and capabilities of real people, not images of the ideal.

The tendency for disability to fall below the radar of public and political attention

The disability movement in Australia does not enjoy the same prominence as it does in the USA, the UK, Sweden and many other European countries.

Factors contributing to this were thought to include:

- i. The language in which disability is cast (disadvantage, vulnerability, pathology).
- ii. The lack of a human rights tradition in Australia.
- iii. The lack of champions.

LISTENING

The past two decades have seen a strong emphasis on active citizenship and participation. In line with this governments are required to consult and consult regularly. This puts the emphasis on speaking - speaking out, saying your bit, contributing to the democratic process. There appears to have been no parallel development in the art and practise of listening: ensuring that people are heard and feel heard. This has profound implications for marginalised populations, particularly when assumptions about dis/ability are made. Comments such as 'I want to be seen as an adult not a child' were reported from the interview data in relation to adults with intellectual disability. A number of parents reported that their views were not heard if they deviated from the prevailing ethos.

It is possible that the great majority of people with disabilities and their families do not feel properly heard. Factors contributing to this include:

- i. Time. Listening takes time. Aboriginal people regularly warn that things can't be fixed in a day; that hearing and deciding is a long process. But governments, employers and workers don't have much of it; it's a scarce resource. Further, listening may no longer count as the work of the paid support worker, employed to move from family to family and accomplish practical tasks. In the words of one interview participant: 'I wish they had time to just listen to me'.
- ii. The being 'done to' legacy. Interview data with adults who have an intellectual disability suggests that when consultation does take place it is predominantly with families and/or front line workers, not the individuals themselves.

ACTING

General observations

Participants discussed:

- i. The need to move from collecting data and information to solutions. The 'information is there' in previous reports and consultations: we need to effect change rather than collect more and more data.
- ii. The importance of building on positive developments. There have been good things in the past. We should build on them.
- iii. The need for change. It was emphasised that 'much more needs to be done' before people from ethnically diverse backgrounds enjoy the same access to services as the mainstream population. In the case of Aboriginal people with disabilities 'a quantum leap' was considered necessary.
- iv. Time to go forward? It was suggested that Western Australia, previously a leader in the disability field with initiatives such as de-institutionalisation to community-based housing and locally-based coordination of services (LAC), might have been resting on its laurels over the past decade. Promising developments seem to have ossified for many reasons including government accountability requirements that appear to reinforce siloed, constrained responses rather than flexible, innovative responses. As part of a normal organisational cycle, this presents the opportunity to move forward.
- v. A willingness to take risks and admit failure. Participants emphasised the need for 'frank and fearless discussion'; a real consideration of what has worked and what hasn't; a willingness to admit mistakes now and in the future. The Japanese notion of 'honourable failure' was noted: the acknowledgement that a move has failed and a willingness to learn from it and go forward.
- vi. The question of accountability. Under the service provider model, governments retreat from direct responsibility, referring it instead to contracted providers who take up the position of the expert or

specialist. The chain of accountability becomes attenuated under these circumstances, along with the responsibility for acting upon the concerns and issues of families. It is important to close this gap.

Policy and programmatic issues

Participants noted a number of more specific policy factors requiring attention and change.

- i. Failures in policy co-ordination. The division of responsibility between Commonwealth and State Governments in relation to older people is of growing concern given the ageing of the Australian population combined with the trend for this group to develop chronic health issues and disabilities. Younger and older groups of people with disabilities will face a number of common issues as family carers and volunteers are less available and serious competition for community care and support workers magnifies. A cooperative response is required.
- ii. The need to ensure integrated access to mainstream services, developing a more seamless interface between the delivery and location of housing, accessible transport, libraries and other educational and recreational facilities, as well as a range of health and welfare services. This is even more crucial for Aboriginal people who often face a multitude of issues.
- iii. Flexibility and choice. The range of practical options available to people with disabilities and their families remains limited. Families need options that complement the types of 'informal' support they provide.
- iv. More and better information. The language in which information about services is provided can be inaccessible and/or limited to English only. Many people do not know what options exist and/or whether they are eligible for certain services.

- v. Employment and training. The employment of people from Aboriginal and ethnically diverse backgrounds within the disability sector is critical to provide culturally responsive services.
- vi. The lack of services in remote and rural areas. The concentration of specialist services in metropolitan areas remains a major issue for many people with disabilities, with particular implications for Aboriginal people who are more evenly spread across WA than other groups.

PRESSING CONCERNS

Participants considered a range of pressing issues needing the attention of Disability Future Directions 2025. These fell under two headings:

- Structural/societal factors
- The needs of particular populations.

Structural/societal factors

The intersection of economic, demographic and environmental changes has profound implications for people with disabilities and/or their carers.

- i. Poverty and low income. People with disabilities and their families have not shared in the benefits of the economic boom. As far as future economic trends are concerned, it was noted that people on fixed incomes suffer most during periods of high inflation and/or economic uncertainty. This stands to be exacerbated by the increase in energy costs, affecting transport and a range of household items.
- ii. Housing. The increase in housing prices in Perth and regional centres has significant implications for people with disabilities. Any scaling down of the public housing sector will force many families to consider private rental with implications for housing design and accessibility as well as cost. There is already something

approaching a public housing crisis in Perth with very large waiting lists. This seriously exacerbates the situation.

- iii. Transport. Over and above the rising cost of travel, 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. An extension of the public transport system, friendly to people with disabilities or with significant fuel subsidies, will be important.
- iv. Employment. There is a significant lack of satisfying, well-paid employment opportunities for people with disabilities.² The availability of meaningful employment was viewed as pivotal to living a satisfying life for most Australians and should be equally available for people with disabilities. This issue was identified as a major knowledge gap with more research needed on:
 - o Different sector opportunities for the employment of people with disabilities.
 - o Differences between employment practices in the public and private sector.
 - o Commonwealth and State responses and obligations.
 - o The attitudes of employers.
 - o The situation of those facing intersecting patterns of disadvantage - eg Aboriginality and disability.
 - o International developments.

The needs of particular populations

Attention was drawn to the particular issues confronting:

² The Commonwealth JobAccess program has recently received a United Nations (UN) Public Service Award in the category of service delivery. It aims to provide people with disability and/or mental illness with greater access to the job market through a one-stop information shop, including online application forms, a database of workplace adjustments and solutions and free expert telephone services.

- i. Aboriginal people. The poverty, poor housing and unemployment experienced by many Aboriginal people stand to be particularly profound for those with disabilities. The prevalence of disability within this population and the high levels of unmet demand for services were noted and their implications for the affordability, availability and the acceptability of services stressed.
- ii. CaLD groups. Western Australia has a high proportion of CaLD groups with more on the horizon. Refugees who have experienced war, torture and/or long-term incarceration are an important group with highly specialised needs. The cultural relevance of services remains a major issue.
- iii. Older people. The proportions of people aged over 65 years, both the 'young old' and the 'old old', are set to grow. In addition, Aboriginal people and people with disabilities tend to show features of ageing much earlier than other people. As noted above, this has significant implications for the co-ordination between State and Commonwealth governments.
- iv. Carers. The economic and social contribution of carers, and government reliance upon it, was emphasised. The work they undertake has significant costs for them in terms of their income, workforce participation, housing and education. The importance of complementing their work by a range of government and community services is crucial.³

³ These and related issues can be found in the submissions to the current House of Representatives inquiry into Better Support for Carers Interestingly, at least the submission from the National Council on Intellectual Disability makes the point that 'carer' was not a term the majority of their participants identified with as they felt it demeaned the love they felt for their child. They preferred, instead, to be simply called 'mum' or dad.'

In conclusion

These are pressing issues inviting both new approaches and the further development of promising trends. Within this context, framing, listening and acting form part of a reflective-iterative process that will shape the nature and helpfulness of Disability Future Directions 2025. Their relationship is interactive and intersecting. Considerations relating to process - how people are heard, data is gathered, information presented and services delivered - are likely to be more important to Future Directions than the setting of specific objectives and targets.