

What the Future will be like in 2025: Analysis of Stakeholder Responses to Stage One Questions

Prepared by Anne Banks-McAllister

1. Introduction

In 2007 the Disability Sector Health Check committee recommended the development of long-term future directions for disability in Western Australia which would benefit all Western Australians with disabilities, their families and carers. The process will envision future directions to 2025 and will inform developments within the disability sector and other government agencies as well as the community and key business corporations.

Stage One of the Disability Future Directions 2025 process involved an environmental scan to gather information about what life in Western Australia will be like in 2025, the trends that will shape the future and the types of opportunities and challenges that will impact on the lives of people with disabilities, their families and carers on the journey from 2008. This information was gathered in a number of ways.

- A series of monograph papers explored current and future trends across a range of economic, workforce, technological and disability areas. These papers raise critical issues to address when developing future directions.
- A summary of issues raised and key questions to be addressed during Stage Two was prepared in consultation with authors (Heading in Helpful Directions paper).
- People with disabilities, their families, carers and service providers were asked to consider the future and answer questions about what they are likely to experience and the challenges and opportunities they may face. In order to get a wide range of opinions, consumer groups and agencies representing a range of ages, disabilities, geographical locations and cultural groups were approached. In addition, the state committee of National Disability Services in WA (NDS) and directorates of the Commission were invited to share their views.

Stage Two of Disability Future Directions 2025 will involve analysis of Stage One information, development of broad future directions and extensive consultation.

2. Methodology

A series of eight Stage One questions (Attachment 1) were intended to elicit a wide range of stakeholder opinions to feed into the Disability Future Directions 2025 process. As the sample was small and not random, it is not possible to make inferences about how many stakeholders in the disability sector hold a particular view. However, where the same view was raised consistently across participants, this is acknowledged, in the understanding that further sampling would need to occur to determine whether this trend is, indeed, accurate.

A total of 70 responses from individuals and groups to eight questions posed were received. A number of people, groups and agencies were approached to participate in individual or group discussions. In addition, a general request for interested people to respond was placed on the Commission's website, staff intranet, by email to funded agencies and in Commission newsletters. Responses were received from a range of people including:

- people with different disabilities of different ages, for example young children with autism, tertiary students with a disability;
- families with children of various ages – some children living at home, some in the community and some in disability accommodation;
- disability agencies and the National Disability Services state committee and a regional committee;
- members of the Ministerial Advisory Council on Disability;
- members of the Aboriginal Advisory Committee to the Commission and Aboriginal staff;
- stakeholders from country and metropolitan areas and from a variety of cultural backgrounds; and
- Commission staff from each directorate.

Responses were reviewed question-by-question and common themes for each question identified. It should be noted that many comments apply to several themes and several themes are closely inter-related.

3. Summary of Findings from All Questions

Overall, stakeholder responses to the eight questions highlighted the following priority issues to be addressed in Disability Future Directions 2025.

- Need for strong leadership
- Service delivery built on collaboration and partnerships
- The impact of changing demographics, in particular the growth in population, the ageing population and the impact of immigration

- The need to support families and carers
- Flexible, lifelong, person-centred planning aimed at creating independence
- Cost of living
- Access to transport and housing
- Inclusion and community attitudes
- Funding
- Reducing bureaucracy
- Sustainability of the sector

4. Question 1 - Describe your vision for the lives of people with disabilities, their families and carers in 15 to 20 years time.

The following aspirations were given in response to this question.

(1) The future vision for people with disabilities is strongly linked to greater community awareness about the value and strengths of people with disabilities and their total inclusion into mainstream community life. Without exception, all respondent groups indicated this aspiration to be the key component of their future vision.

Representative comments included:

- 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.
- That people with disabilities have relationships with people and participate in society. Relationships are critical.
- People with disabilities are valued and contributing members of the community, not a marginalised or 'special' group that requires 'specialised responses'.
- All people live in welcoming communities that provide friendship; mutual support and a fair go for everyone, including people with disabilities, their families and carers.
- For every person in WA to have a person with a disability in their social network.
- 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.
- 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.

(2) The theme of 'Choice and Access to Support' was well supported and related to the provision of on-going funding, options and choice, 'person-centred' planning and delivery, equity of access including geographic, and continuity of support.

Representative comments included:

- People living in rural and remote areas of the state receive equitable, appropriate services and supports that allow them to remain living in their communities.
- More 'person centred care' model.
- Families and individuals have the supports they require to plan and achieve a vision for their lives.
- 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 access generic service systems and there are no specialist disability services or programs.
- A wider choice of providers. Flexible supports.
- 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.
- Guaranteed individual support is possible through appropriate funding.
- One stop shop to provide all services eg case management/service coordination.
- 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.
- More hours funded for intervention and intervention that carries on indefinitely – for as long as it is needed.
- Government allowances to help fund living.

(3) The theme of 'Support for Carers and Families' involved a strong emphasis on appreciating and building on positives and strengths.

Representative comments included:

- For those carers who are getting older there should be support coming into the home to help with 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.
- Carers to be valued and well paid career path – respected and valued by the community. Also that it is a man's as well as a woman's job.
- More financial support for families and carers.
- Families supported in more positive and protective ways. Protected from dire things (eg predictions as to limitations) which break family's spirit. Rather focus from early on, on the positive strengths – the good life.
- Families as partners.
- Families are resilient and strong and are supported in their capacity to determine and achieve a good life.
- 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.
- 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.

(4) The theme of 'Independent Living' related to accommodation and the need to ensure independence from parents, especially as parents age.

Representative comments included:

- 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, not just somewhere that safety isn't certain. There should be security and support for people to give whatever help is needed, and to check and make sure that everything is alright. I've been thinking of perhaps something like a village, a bit like a retirement village where people can either have their own little house or share with others.
- Independent living options across the whole of life – not just based on disability but on whole of life enjoyment.
- Accessible housing for all and all the supports that are necessary for this.
- Supported accommodation with adequate funding and support eg health related problems
- Aging in place.
- People with disabilities live where they want, how they want, and with whom they want. People with disabilities and their families are not held at a disadvantage because they make their home in rural and remote WA.
- More community-based independent living.
- If people with disabilities are not going out to work, they should be able to go out every day during the week. It is no good for them not to be meeting other people and doing interesting things. They need some distractions, not just staying at home, losing skills and watching television. This will help people with disabilities get used to not being with Mum and Dad all day, every day and help prepare them for one day when they don't have Mum and Dad anymore.
- [Carers] need peace of mind on "Who will care when I'm gone".

(5) All respondents indicated the need for continuing focus on universal access, particularly around public transport and public buildings.

(6) Several comments were also made around the human rights of people with disabilities and the use of emerging technology for access and health benefits.

"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."

“To create a centre of excellence for disability engineering - recreation, housing, mobility, fitness, employment, transport opportunities.”

(7) There was a strong aspiration for involvement of all levels of government in disability issues together with greater inter agency cooperation.

5. Question 2 - What factors are going to make the biggest difference to society in Western Australia over the next 15 – 20 years?

A triple bottom line approach was used to broadly group the many responses into themes of Social, Economic and Environmental. The following sub-themes were then identified as follows:

Social

- Changing Demographics
- Community/Family Sustainability
- Social Inclusion
- Housing Options
- Education and Training
- Health and Disability
- Access to Services
- Safety and Security
- Social Policy

Economic

- Cost of Living
- Technology
- Globalisation
- Employment
- Funding
- Economy

Environmental

- Energy Crisis
- Climate Change
- Population Growth

Responses were initially analysed by each respondent group and then combined. Overall, the majority of comments fell into the Social and Economic themes, with Social comments recording a slightly higher number of responses. Significantly fewer comments were recorded against the Environmental theme.

Social Theme

Within the Social theme, most comments were recorded against Community/Family Sustainability followed by Changing Demographics. Social Inclusion recorded the next highest, with the remaining sub-themes recording significantly fewer comments.

(1) Overall respondents believe that issues around Community and Family Sustainability will have the greatest impact in the future. Issues were identified as:

- Impact of Y Generation – generational differences
- Breakdown of traditional family structures
- More insular community - individualism versus collectivism
- Changing work patterns eg fly in/fly out, having an impact on family
- Greater cultural diversity leading to tensions

Representative comments relating to 'Community and Family Sustainability' include:

- Resource industries inability to recognise the significant positive impact of building community and supporting families to live locally. Fly in / fly out workforce results in limited support networks and community capacity.
- Changing structure of family life driven by other demands that people are expected to aspire to eg increased hours of work, career advancement, relocation. This means that families own cohesive family unit is not available as people desire and are encouraged to pursue opportunities. Extended informal supports tend not to be available to families and yet the system increasingly expects families to call on these supports.
- 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.
- Asian concept of disability and stronger focus on the broader family relationship including PWD will eventually change our attitudes.
- YGens versus baby boomers – lack of responsibility by Y Gens.

(2) Respondents believe that changing demographics, in particular the ageing of the population and the impact of immigration will also have a significant impact on society in the future. Issues were identified as:

- more people with a disability
- increased longevity of people with disabilities
- increased complexity due to cultural/ethnic mix
- reduction in the number of carers in relation to the number of older people

Representative comments relating to 'Changing Demographics' include:

- Increase in the diversity of the population and the needs of diverse groups. Greater competition for social and financial resources. Broader complexity of social issues and problems. Increase in the number of PWD requiring assistance.
- 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.
- 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.
- Ageing of the population: 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.

(3) Respondents believe that the next most important impact on society in the future will be around attitudes to disability and society's ability and willingness to include people with disabilities in community life.

Representative comments relating to 'Social Inclusion' include:

- 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.
- 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.
- 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. If we end up with a nationalistic (tribal, local, territorial) response to challenges we will not find sustainable solutions.
- 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 savvyness 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.
- 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.

Economic Theme

(1) Within the Economic theme, most comments were recorded against the Cost of Living followed by Technology

Overall respondents' comments on the impact of the Cost of Living, in particular the impact of the resources boom, related to an increasing gap between rich and poor, or the 'haves' and 'have nots'. The cost of petrol, food and housing were highlighted most often. The issue of poverty was raised frequently. It is important to also consider comments categorised under the themes of Employment and Economy to further understand contributing factors to the Cost of Living.

Representative comments relating to 'Cost of Living' included:

- 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.
- Pricing will become the tipping point for change.
- 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. Working people find it difficult to cover the costs of the basics of living (like housing, food, transport) no matter how hard they work. The basics will be less affordable.
- We are in a boom but there are no services – the boom is creating a two tier town.

(2) The theme of 'Technology' received the second highest number of responses overall, particularly in relation to assistive technology and medical technology, particularly early screening for disabilities.

Representative comments included:

- Advances in medical technology, and screening at early stages of pregnancy.
- Technology- improvements in equipment and technology will increase the independence of PWD by assisting with tasks of daily living and opening up new work opportunities. Improvements in medical treatments will improve survival rates for babies and people with severe illness or disability, whilst also improving the health and life expectancy of many PWD. Advances in genetics will create new issues and decisions for individuals and families.
- Impact of advances in medical technology on the incidence of disability eg keeping people alive after traumatic injury, fertility treatment, post-natal care for premature babies. An increased incidence of disability will increase demand on families and/or increase demand on services.
- Neo-natal screening technologies – the more families struggle, the less likely that people will knowingly give birth to a child with a disability. Expect that professionals will advise parents to terminate. Possibility that the system will force families to take individual responsibility if they have a child with disability.

Environmental Theme

In comparison to the other triple bottom line theme, the Environmental theme received the least comments, however there was the highest amount of interconnection between the sub-themes and comments. Population Growth received the highest number of comments, followed by Energy Crisis then Climate Change. Overall it is clear that respondents believe that Population Growth, the Energy Crisis, and Climate Change will have impacts on transportation (fuel prices), access to services, sense of community (localisation), and town planning.

Representative comments relating to 'Population Growth' included:

- I think that the population growth of WA will keep growing and that will make it harder for people to get jobs, including PWD and older people
- Urban expansion will impact transport costs and the establishment of infrastructure and support services.
- Population growth through increased migration.

Representative comments relating to 'Energy Crisis' included:

- 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.
- Urban planning to improve proximity to schools, shops, transport.
- Oil crisis is not a temporary blip. Airlines will reduce flights; travel and infrastructure is all around the car – Perth is car dependent and this will exacerbate access and hence vulnerability of those with a disability.

Representative comments relating to 'Climate Change' include:

- There is an increasing focus on the environmental impacts on our daily lives. Public opinion will require more planning of new infrastructure such as buildings, public transport to achieve sustainability and global standards in use of resources such as power. There will be a focus on less private use of cars and an expectation of infrastructure and services for leisure, retail, etc in a local area.
- Climate change and associated increase in living costs and changes to modes of transport and energy.
- Will climate warming change people's attitudes and behaviours? Will climate change draw us back to local communities?

6. Question 3 - What are the key factors that will most affect the lives of people with disabilities, their families and carers? What effect will each factor have?

Responses to this question were analysed separately for the four respondent groups and then combined by theme. The top three factors were then identified across all respondents.

Most respondents indicated many more than three factors and no priority was provided. A large number of themes were identified:

- Economy and Cost of Living
- Carers and Support
- Inclusion
- Third Sector
- Corporate Sector
- Ageing Population
- Workforce
- Integrated and Accessible Service Delivery
- Technology
- Energy Shortage
- Funding
- Employment
- Housing
- Information
- Health Care
- Education
- Law and Order
- Population Growth
- Immigration
- Demographics
- Legislation
- Environment

The top three factors were identified by the number of comments received. These were:

1. Inclusion;
2. Funding; and
3. Economy and Cost of Living (equal).

The issue of community attitudes, integration and acceptance of people with disabilities were the most significant factors emerging from the responses. The

inclusion of people with disabilities (differences) into mainstream society was clearly identified as a key driving factor.

Representative comments relating to 'Inclusion' included:

- Community accessibility and acceptance. Need to move beyond our understanding of 'physical/mobility' access and towards a broader idea of access. The more people with disabilities 'emerge' the more that acceptance will improve.
- Success to which people with disabilities are seen as a person/citizen first and therefore eligible for support the same as everyone else and their needs accounted for.
- Education to change community attitudes.
- 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. Impact – people have to get paid to get support for people with disabilities. Volunteering is decreasing.
- 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 215, 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.

The next key factors of Funding and Economy and Cost of Living were equal in priority across all respondents. In the 'Funding' theme the equitable distribution of funding; continuity of funding; funding collaboration; and sufficient funding to service providers and families, were raised as the most significant issues.

Representative comments relating to 'Funding' included:

- Government resources not shared equitably in the community
- That essential services are not reliant on fund-raising
- Government funding – allowing growth to meet existing unmet needs and allow for proactive planning. Greater collaboration of funding bodies. Families should be able to access a 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. Reducing overlap will ultimately save money as you reduce duplication of case management and admin costs.

- Without money would not be able to access paid services such as therapy, diagnosis, support/carers, baby sitting.
- Cost of disability and what will be covered by government, through health insurance and what will be user pays. Continued tension between government to be a direct service provider of service for people with intellectual and other disabilities and the community to manage its responsibilities.
- Funding – cost of care may force change in models of service delivery.
- 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.

In the 'Economy and Cost of Living' theme, respondents raised issues of Government policy; Government's capacity to fund; the impact of fuel pricing and house/rental prices; and the growing gap between rich and poor.

Representative comments relating to 'Economy and Cost of Living' included:

- Impact of economic boom dividing community into rich and poor. Impact – Government seems to pour resources into economic boom not social needs.
- Economic impact ie cost of living, results in people with disabilities dependent on the family of the State and exclusion from participation in workforce which heightens dependence.
- 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.

7. Question 4 - What things will be of most help to achieve your future vision for people with disabilities, their families and carers?

Responses to this question were analysed separately for the four respondent groups and then combined by theme. A large number of factors were identified and these were categorised into 14 themes as follows:

- Workforce Issues
- Inclusion and Community Attitudes
- Funding and Resources
- Service Delivery
- Leadership and Strategy
- Education
- Corporate Social Responsibility
- Universal Access
- Carers and Family Support
- CaLD
- Technology and Research
- Information
- Employment
- Accommodation

The themes that received the highest number of responses in priority order were:

1. Service Delivery
2. Leadership and Strategy
3. Funding and Resources
4. Carers and Family Support
5. Education
6. Inclusion and Community Attitudes
7. Workforce Issues
8. Technology and Research
9. Corporate Social Investment and Universal Access

(1) Comments related to the 'Service Delivery' theme focused on the coordination of service delivery across providers; planning and service delivery for all life stages of people with disabilities and their families; flexible service delivery around the individual; independence for the person with a disability; and access to mainstream services.

Representative comments relating to 'Service Delivery' included:

- Self-management of services – change service delivery model from care/therapy directed to clients being facilitated to take greater control over outcomes
- Consciously structured and planned lives for people with disabilities, not hit and miss. Example of individual education plan (IEP) something that continues, the spoke in the wheel changing with needs and life stages, a bit like the PIN model.
- Need a framework that distinguishes between the condition; the emotional consequence of the condition; and the impact on daily life. Requires a cross-sectoral approach. Have to make our systems more responsive to cross-sectoral work.
- Real planning from birth and better use of funding. Planning at key life-stages including the whole family. Re-invigorate the LAC role as it was originally intended – case management.
- Partnership/convergence between health, aged care and disability.
- People with disabilities to be encouraged to take ownership of life.
- That people with disabilities can access an appropriate 'package' of support that ensures their ability to live with dignity and equity in their chosen neighbourhood.
- Recognition of the diversity of people with a disability and ensuring that they have genuine choice of services, not just mainstream services.
- Better partnerships between governments and care organisations and families and people with a disability in problem identification and solutions.
- Focus on regional service development – core locating, funding to retain people in the area; policies for regional development; focus on indigenous and remote programs.
- Reduce some of the costs of disability by improving access to mainstream services and community.

(2) The theme of 'Leadership and Strategy' received the second highest number of comments. Comments related to concepts such as effective communication; shared vision; empowerment; partnerships and collaboration; encouraging change; and planning based on good information.

Representative comments relating to 'Leadership and Strategy' included:

- Build a strong 'third sector' identity with leadership – disability, welfare and community groups are siloed.
- Leaders who lead by example and are high profile – who embrace disability and don't dodge it.
- Question how successful the 'Adopt a Politician' has been as a strategy for raising awareness. While it is hard to measure the impact of the scheme, it has raised the awareness and has probably facilitated the recognition of the voice of carers.
- Need better data, research and information for better planning.
- Australia's ratification of the UN convention on the Rights of Persons with Disabilities and implementation of policies, programs and services to achieve its objectives.
- A public vision or direction for DSC which will guide cohesive development of policy and operational decisions across all Directorates.
- Creation of an environment where innovation is valued and the involvement of people outside the sector to have input to new strategies is encouraged.
- Greater role for local government.
- Stronger advocacy – political influence/championing
- Continued leadership by government – employment, legislation, community awareness programs
- Need vision and leadership. Need people to make hard decisions. A willingness to do things differently and embrace change.

(3) The theme of 'Funding and Resources' received the third highest number of comments. Comments related to moving control to families; insurance schemes; funding for prevention; tax subsidies; sustainable funding for non government agencies; and seamless funding across life stages of people with disabilities.

Representative comments relating to 'Funding and Resources' included:

- National Disability Scheme – potential for greater predictability and certainty.
- Tax concessions or concessions by local government to encourage and support families to make arrangements for ongoing care in the home.
- Shift locus of control to families. Risks are minimal. People will spend the money on what they need. This was the driver of the LAC model as it was originally intended. We have developed very restrictive notions around how money can be used.
- More funding for preventative measures.
- Continuous funding from Government for a variety of things that affect the lives of people with disabilities – free public transport everywhere transport supports channeled through Centrelink; improved taxi subsidies, etc. Free technological support for those who need it.
- Non government sector remaining sustainable and values-based.
- That priority funding be given to respite funding that has a focus on transitional options and futures planning.
- Recognition by Government of the need to support expert organisations and remove reliance on fund-raising for provision of services. Recognition and financial support by Government for the part that expert organisations play in providing expertise to stakeholders other than clients and their families.
- A new funding stream - such as the Victorian TAC or similar to the Medicare Levy. Commonwealth is discussing a Catastrophic Injury Insurance.

(4) The theme of 'Carers and Family Support' received the next highest number of comments. Comments related to family self-management; training for parents; sibling involvement; partnerships; choice; and recognising the role of families. The PIN Model was also raised for further discussion.

Representative comments relating to 'Carers and Family Support' included:

- Enter a Social Contract where family carers do their bit as best they can, and the community will make up the shortfall.
- Encouragement of personal initiatives eg incentives for families to look after themselves. Encourage independence eg through facilitative community groups like PIN.
- Need more innovative options such as sharing care between families. Enable people to let go of control.
- Need to have a continuum of support options available to people but there has to be real choice. Some individual and group options are OK. Current shift to outcome measurement is a good step.
- More therapy and within home and training for parents
- Families should have the basics (continence aids, specialised food, medical) provided for them so they can use their own resources for other things.
- Knowing where our son is going to live. He will have a place to live where he will be cared for properly so that we don't have to worry about what will happen to him anymore. We would like our older son to be included in his life, to help him make decisions, look out for him and having him to stay over.
- A community-based reliable 'sitter service'. This could make a huge difference not only to the quality of life of people with disabilities and their families. It could also potentially reduce the reliance on more expensive and less flexible respite-type services.
- A more rigorous and informed advocacy for individuals who do not have a family/personal advocate other than the State.
- Greater self-management for families. DSC has gone from self-management to shared management for accommodation and ATE. A backward step. Need to empower and educate parents about what is possible. Allow parents to make informed choices and support them to make and exercise their choices. PIN and Microboard won't suit all families and there has been long term evaluation of their ongoing sustainability. There is nothing in between crisis on one hand and purely independent on the other.
- Openness to new solutions that families identify that are usually not supported.
- Would like to see families supported to come up with and implement their own solutions that are both innovative and practical.

Other significant key issues raised in response to this question related to:

- Impact of workforce issues on availability of carers
- Inclusive education
- Role of the corporate sector
- Access particularly to public transport
- Use of technology

8. Question 5 - What things might stand in the way of your vision becoming a reality?

Responses to this question were analysed separately for the four respondent groups and then combined by theme. Comments were categorised according to the following nine themes:

- The Establishment (government, bureaucracy)
- Lifelong Planning
- Attitudes to Disability
- Service Delivery
- Funding and Resourcing
- Global Issues
- Innovation
- Transport
- Community Sustainability

The majority of comments related to 'The Establishment'. This was followed by Funding and Resourcing; Service Delivery; and Attitudes to Disability.

(1) Overall the theme of 'The Establishment', received the highest number of comments, most relating to too much bureaucracy; existing power structures' vested interests; top down policy development; entrenched views; susceptibility to government change; and over regulation.

Representative comments about 'The Establishment' included:

- Too radical and too threatening to existing power structures.
- Politics of the disability sector – kingdoms.
- Entrenched views – who has the most to gain or lose by change? Who has the most power?
- Too much red tape and bureaucracy.
- Bureaucratic way of thinking. More people in bureaucratic roles and less people doing the hands-on work.

- Derogatory Government policies – that is top down imposition of decisions without consultation with individuals and their families and carers.
- Policy changes that will increase red tape and make life harder.
- A poor Minister post-election which will fail to raise the profile of disability.
- Vested interests – maintaining silos, empire building, increased bureaucracy and complexity.
- Loss of disability identity – merged with other portfolios.
- Over regulation. Over compliance. Cost of bureaucracy. Conflict between State and Commonwealth, Conflict age versus disability. Poor governance. Red tape. Government short term vision.
- Egos and ulterior motives – State versus Commonwealth blame shifting culture and reluctance to acknowledge the depth of the issues and this them means they will need to fund solutions.
- Wide variance within local government of disability responsibility, especially in regard to housing.

(2) The theme of 'Funding and Resourcing' received the second highest number of responses. Comments related to decreasing funding; changing government priorities; lack of equity; focus on mainstreaming to save money; piecemeal funding; and complexity.

Representative comments about 'Funding and Resourcing' included:

- Lack of skilled and experienced support workers.
- Piecemeal funding for different projects. Projects which would benefit all may be funded by various organisations and thus there are different criteria for participants. This leads to exclusion of many due to factors such as age. So hard to compete for funding.
- Disturbing trend of mainstreaming.
- Failure to fund specialist multi-cultural service providers.
- Lack of equity across the sector.
- Complexity of funding.
- Competing demands and priorities.

(3) The theme of 'Service Delivery' received the next highest amount of comments. Comments related to expectations; the availability of carers and staff; cultural awareness (CaLD and indigenous); difficulty in accessing services; and the role of Local Area Coordinators (LACs).

Representative comments about "Service Delivery" included:

- iExpectations by the disability community that government must do everything. Government only represents 2% of the value of the economy. If government doesn't do its business effectively and efficiently then it can't survive. Many in the disability community think this counteracts a caring culture.
- Lack of active engagement by LACs.
- Not being able to get appropriate services (therapy, etc) due to money or access. No support from family.
- The sense that it is too hard in rural and remote areas and therefore less than the best is OK.
- Lack of suitable/qualified staff – attraction and retention.
- Western culture in the delivery of services.
- Expectations of younger people currently accessing services.
- Expectations of new families of people with disabilities – relationship to current practice/funding.
- Assumptions about the availability of 'natural' supports (family)

(4) The next most significant theme was 'Attitudes to Disability'. Comments related to the profile of disability; community ignorance and attitudes; and discrimination.

Representative comments about "Attitudes to Disability" include:

- 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 doesn't have the profile or scale that ageing does but there are many possible spin offs for people with disabilities from ageing. One of the positives from the ageing of the population will be that there will be more older people in better health and better able to direct and manage the support they need.
- Preconceptions of people often limits what is available – if attitude changed then this would lead to scope for more things.
- 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.

9. Question 6 - *What are your fears or concerns for people with disabilities, their families and carers over the next 15-20 years?*

Responses to this question were analysed separately for the four respondent groups and then combined by theme. Comments were categorised according to the following fourteen themes:

- No Change
- Service Delivery
- Education
- Institutionalisation
- Isolation
- Funding
- Care and Family Support
- Attitudes to Disability
- Cost of Living
- Accommodation
- Employment
- Workforce
- Changing Demographics
- Government

Most comments were recorded against the following themes in priority order:

1. Service Delivery
2. Family Support
3. Isolation and Funding (equal)
4. Attitudes to Disability

(1) The theme of 'Service Delivery' received the highest number of comments. These related to demand; lack of trust in families; increased mainstreaming; loss of specialist services; and equity.

Representative comments about 'Service Delivery' included:

- That specialist services will be eroded. Responsive mainstream services will not be enough.
- That the problem of providing services will become so big it will become an excuse not to address it.
- That information about best practice models is not communicated to families. Families need to be told that it is not good for people with disabilities to stay with their families forever. Need to promote independence and a normative life course for people with disabilities.

- [Fear that we will] Get away from the model of disability having its own department – provides an ‘out’ for mainstreaming departments. Lack of co-operation not only between the Commonwealth and the State but also between the DSC and other departments.
- Lack of trust in families.
- 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.
- No separation of regulator/funder from service delivery.
- That the interface between health, disability or ageing will remain static. Access to HACC and CACPs will remain unclear and hard work.
- The disturbing trend of ever increasing mainstreaming will continue.
- That planning and emphasis is 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.
- Fear that people with disabilities will be neglected with health and mental issues.
- 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.
- Capacity of private accommodation facilities and other service providers to deal with people who have challenging behaviour and complex needs to manage.
- Increased demand for, and cost of, resources may result in pressure to provide more expedient service models that move away from a person-centred focus.

(2) The theme of ‘Care and Family Support’ received the second highest number of comments. It is important to recognise that there are close synergies between this theme and the top theme of ‘Service Delivery’.

Comments in relation to ‘Care and Family Support’ related to family isolation; capacity to care; and ageing carers.

Representative comments for ‘Care and Family Support’; included:

- That families will become increasingly marginalised and that the risks of abuse will 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.
- That the needs of indigenous families will be understood, poorly planned and inappropriately funded.
- 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.
- Carers stress and burnout.
- The availability of viable options, supports and placements for people with disabilities as they age. Their direct family and carers will also be ageing and be in no position to continue their care.

(3) The theme of 'Isolation' received the next highest number of comments, equal to the theme of 'Attitudes to Disability'. Comments in relation to this theme should be reading conjunction with the 'Attitudes to Disability' theme.

Comments about 'Isolation' related to marginalisation; disadvantage; CaLD; and non-inclusive communities.

Representative comments for 'Isolation' included:

- Lack of awareness, understanding and acceptance of diversity of society. Need to filter through schools and workplaces. Inclusion is a good idea but the reality is different. Requires a shift of mindset.
- 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.
- That certain groups of people, with disabilities and caring for them, will become more disadvantaged and isolated.
- That those with the highest support needs will become marginalised at edge of society physically and socially.
- Isolation due to communities not being designed to be inclusive enough. Some good planning being done – needs to be extended eg high density around railways.
- 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.

(4) The 'Funding' theme received the same amount of comments as 'Isolation'. Comments related to managing demand; increasing capacity; reduction in funding; loss of specific funding; increasing costs; choice; lack of flexibility; and cost cutting.

Representative comments for 'Funding' included:

- That the individualised trend towards individualised funding could lead to 'nominal' allocation of funds but with limited choice of services. Individualised funding is based on values that are attractive but in practice has failed to deliver. Rhetoric about flexibility. See "In Control" organisation in UK as an example of flexible funding.
- Inflexible government funding, inappropriate indexation levels and no real growth in funding.
- That sufficient focus and funding will not be given to the importance to carers of planned breaks, respite, transitional planning as an alternative to lack of permanent accommodation funding options.
- Availability of funding for people with complex care needs who require specialised services.
- Impact of cost cutting in agencies on the quality of care provided for consumers.

(5) The theme of 'Attitudes to Disability' was closely related to the "Isolation" theme. Comments related to hierarchies of disability; misconceptions; stereotypes; and community fear.

Representative comments for 'Attitudes to Disability' included:

- That the disability community will fracture eg between intellectual disability and non-intellectual disability, or between carers and people with disabilities.
- Labeling.
- Social perception and stereotypes.
- 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.

There were significant comments in other themes that should be taken into consideration. In particular, there was much fear expressed (14 comments) that there will be no change.

There were also a number of comments (14) indicating a fear that institutionalisation will be reintroduced for people with disabilities, in particular due to economic rationalisation. Institutionalisation in relation to Aboriginal people and people with mental health issues was particularly highlighted.

10. Question 7 - What is the most important thing you would like to tell people who are developing future directions for disability?

Responses to this question were analysed separately for the four respondent groups and then combined by theme. Comments were categorised according to the following eight (8) themes:

- Leadership
- Employment
- Person Centred Planning
- Families and Carers
- Community Awareness and Attitudes
- Services and Information
- Funding
- Innovation

Comments resulted in the following priorities:

1. Leadership
2. Person Centred Planning
3. Families and Carers
4. Services and Information
5. Community Awareness and Attitudes
6. Innovation
7. Employment

(1) The theme of 'Leadership' received a significantly higher number of comments than the other themes. Comments related to vision; leaders; partnerships; listening; trust; focus; and good decision-making.

Representative comments for 'Leadership' included:

- Must have integrity of vision. Build in disability services principles.
- Have recognised leaders who are willing to speak about disability.
- Use good research/evidence based data for decision-making.
- 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. Consultation and active participation is vitally important to the fulfillment of PWD needs, issues and agendas, ultimately with the goal of achieving the fulfillment of their human rights.
- Ensure a whole-of-government approach to disability – building better pathways, reducing barriers across sectors eg ageing and disability.
- Ensure specific and continued focus on disability with dedicated funding, Minister, government portfolio.
- 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. PWD are not an homogenous group. Many will need little more than environmental modification to assist them 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 it to have something to say and something to offer this large and very vulnerable group of people, their families and carers.
- Outcome should be improved CaLD/disability leadership, inclusion and transparent accountability, resilience and consistency in meeting the actual CaLD/disability needs.
- KISS – keep it simple.
- Other agencies need to take on commitment to provide services for Aboriginal people.

(2) Person Centred Planning and using a strengths based approach received many comments (21).

Representative comments included:

- 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. They can't plan for themselves on their own – we need others to help and give us a hand. We need to know things so that we can plan.
- Make the service fit the person rather than the other way around.
- Strengths/assets approach to planning

11. Question 8 - Who else should be involved?

A range of stakeholders were identified. Participation by relevant Local, State and Commonwealth government departments was identified as critical, as was the involvement of people with disabilities and their family, siblings, friends and carers.

The Corporate sector was also identified as important stakeholders and several significant business people were specifically included.

Attachment 1: Eight Stage One Questions

In answering these questions, you may wish to think about people with disabilities, their families and carers who are similar to people you know.

1. Describe your vision for the lives of people with disabilities, their families and carers in 15 to 20 years time?
2. What factors are going to make the biggest difference to society in Western Australia over the next 15 to 20 years?
3. a. What are the three factors that will most affect the lives of people with disabilities, their families and carers? b. What effect will each factor have?
4. What things will be of most help to achieve your future vision for people with disabilities, their families and carers?
5. What things might stand in the way of your vision becoming a reality?
6. What are your fears or concerns for people with disabilities, their families and carers over the next 15 to 20 years?
7. What is the most important thing you would like to tell people who are developing future directions for disability in Western Australia?
8. Who else needs to be involved in developing future directions for disability in Western Australia?