



30 April 2014

Ms Karen Wilson  
Branch Manager  
Disability and Carers Branch  
Department of Social Services

Dear Ms Wilson,

Re: National Disability Strategy 2014 progress report to COAG

In response to your request for Carers Australia to provide member feedback on the National Disability Strategy, Carers Australia conducted an online survey of unpaid family and friend carers of people with disability based on the briefing material you sent us on 30 January 2014.

We received responses from carers across Australia. Promotion of the survey was assisted by the network of state and territory Carer Associations.

The results of the survey are in the Attachment below.

Yours sincerely,

A handwritten signature in black ink that reads "Aresswell".

ARA CRESSWELL  
Chief Executive Officer

## **Results of Carers Australia online survey ‘Carer views and insights: National Disability Strategy’ April 2014**

*Results are not to be further distributed or published without prior written permission from Carers Australia.*

Total started survey: 77

Total completed all questions in survey: 53 (68.8%)

### **Summary**

In regards to the National Disability Strategy on-the-whole:

- Although 54.7% of carers responded that they were aware of the National Disability Strategy, the text responses highlight that some respondents were unsure of how the strategy had been enacted or what it could do in a practical sense, and some statements indicate that respondents may have confused the strategy with the National Disability Insurance Scheme. A few respondents stated that through completing the survey they had become aware of the strategy for the first time.
- The majority of carers responded that they were unsure if the general public had acquired a more positive attitude of people with disability in the community since 2010 when the strategy was introduced.

In terms of the six policy outcome areas of the National Disability Strategy:

- The areas that were more positively rated by carers were: 1) health services for people with disability, and 2) community inclusion/participation of people with disability. There were five statements that the majority of carer respondents agreed with, being: “As a carer, I am able to participate in social, cultural, religious, recreational or sporting activities” (25 carers agreed), “The person I care for is able to participate in social, cultural, religious, recreational or sporting activities” (22 carers agreed), “Information for people with disability is accessible and reliable through radio, television, telephone/mobile phone, the internet or social media” (22 carers agreed), “Health service providers (hospitals, general practices, specialist services, allied health, dental, mental health, and ambulance services) meet the needs of

people with disability” (22 carers agreed), “Health services for people with disability are preventative or have an early intervention focus (for example treatment at a certain time can improve a condition or prevent it from worsening)” (19 carers agreed).

- In general, carers most strongly disagreed with statements about the financial security of people with disability (the majority of carer respondents strongly disagreed with each question in this area). The greatest number of carers indicating that they strongly disagreed with certain statements, were as follows: 36 carers strongly disagreed with the statement “Income support and tax systems provide an adequate standard of living for people with disability, their families or carers”, 31 carers strongly disagreed with “People with disability can access well designed housing with choices about where they live”, and 30 carers strongly disagreed with “Housing is affordable and secure in terms of tenure for people with disability - the conditions and rights they have to occupy their accommodation”. Other statements that the majority of carers strongly disagreed with were: 25 carers strongly disagreed with “Employers are aware of the benefits of employing people with disability”, 23 carers strongly disagreed with “Public, private or community transport is easy to access and use”, 22 carers strongly disagreed with “There are opportunities for people with disability to find employment or to establish their own businesses”, 20 carers strongly disagreed with “There are supports in place to assist people with disability to move from school to further education, training or employment”, and 16 carers strongly disagreed with “People with disability can express their concerns or make suggestions to improve their rights and access to justice”.
- Other statements that the majority of carers disagreed with were: “Personal support services (for example paid support workers) and community services for people with disability respond to their particular needs and circumstances, even when these might be complex” (21 carers disagreed), “Education and training for people with disability, from early childhood to adulthood, is accessible and high-quality” (20 carers disagreed), “Health services for people with disability are readily available” (20 carers disagreed), “Health services allow people with disability to choose their treatment or to be involved in the planning of their services” (19 carers disagreed), “Personal support services and community services for people with disability take into account their personal preferences and maximise opportunities for independence” (17 carers disagreed), and “Personal support services and community services include families and carers of people with disability” (17 carers disagreed).

- Carers indicated greatest uncertainty with statements about the financial security of people with disability – 16 carers were unsure if “Employers are aware of the benefits of employing people”, 14 carers were unsure if “There are opportunities for people with disability to find employment or to establish their own businesses”, and 14 carers were unsure if “Housing is affordable and secure in terms of tenure for people with disability in terms of the conditions and rights they have to occupy their accommodation”.

Further analysis of open-ended/text responses is available in the appendix.

### **Section 1: Optional questions on personal details**

#### 1.1 Gender

Female 66 (90.4%)

Male 7 (9.6%)

Other 0 (0.0%)

Count 73

#### 1.2 Identified as being from a culturally and linguistically diverse background

Yes 9 (12.7%)

No 62 (87.3%)

Count 71

#### 1.3 Identified as being from an Aboriginal and/or Torres Strait Islander carer

Yes 3 (4.1%)

No 70 (95.9%)

Count 73

#### 1.4 Type of location where living

Major city 37 (50.7%)

Regional area 27 (37.0%)

Rural area 8 (11.0%)

Remote area 1 (1.4%)

Count 73

## **Section 2: Questions about how people with disability are included in the community and can participate in activities**

2.1 The person I care for is able to participate in social, cultural, religious, recreational or sporting activities.

Strongly agree 4 (6.5%)

Agree 22 (35.5%)

Disagree 19 (30.6%)

Strongly disagree 15 (24.2%)

Unsure 2 (3.2%)

Not applicable 0 (0.0%)

Count 62

2.2 As a carer, I am able to participate in social, cultural, religious, recreational or sporting activities.

Strongly agree 2 (3.2%)

Agree 25 (40.3%)

Disagree 22 (35.5%)

Strongly disagree 12 (19.4%)

Unsure 0 (0.0%)

Not applicable 1 (1.6%)

Count 62

2.3 Public, private or community transport is easy to access and use.

Strongly agree 1 (1.6%)

Agree 19 (30.6%)

Disagree 19 (30.6%)

Strongly disagree 23 (37.1%)

Unsure 0 (0.0%)

Not applicable 0 (0.0%)

Count 62

2.4 Information for people with disability is accessible and reliable through radio, television, telephone/mobile phone, the internet or social media.

Strongly agree 2 (3.2%)

Agree 22 (35.5%)

Disagree 20 (32.3%)

Strongly disagree 15 (24.2%)

Unsure 3 (4.8%)

Not applicable 0 (0.0%)

Count 62

2.5 People with disability can access well designed housing with choices about where they live.

Strongly agree 0

Agree 5 (8.1%)

Disagree 17 (27.4%)

Strongly disagree 31 (50.0%)

Unsure 5 (8.1%)

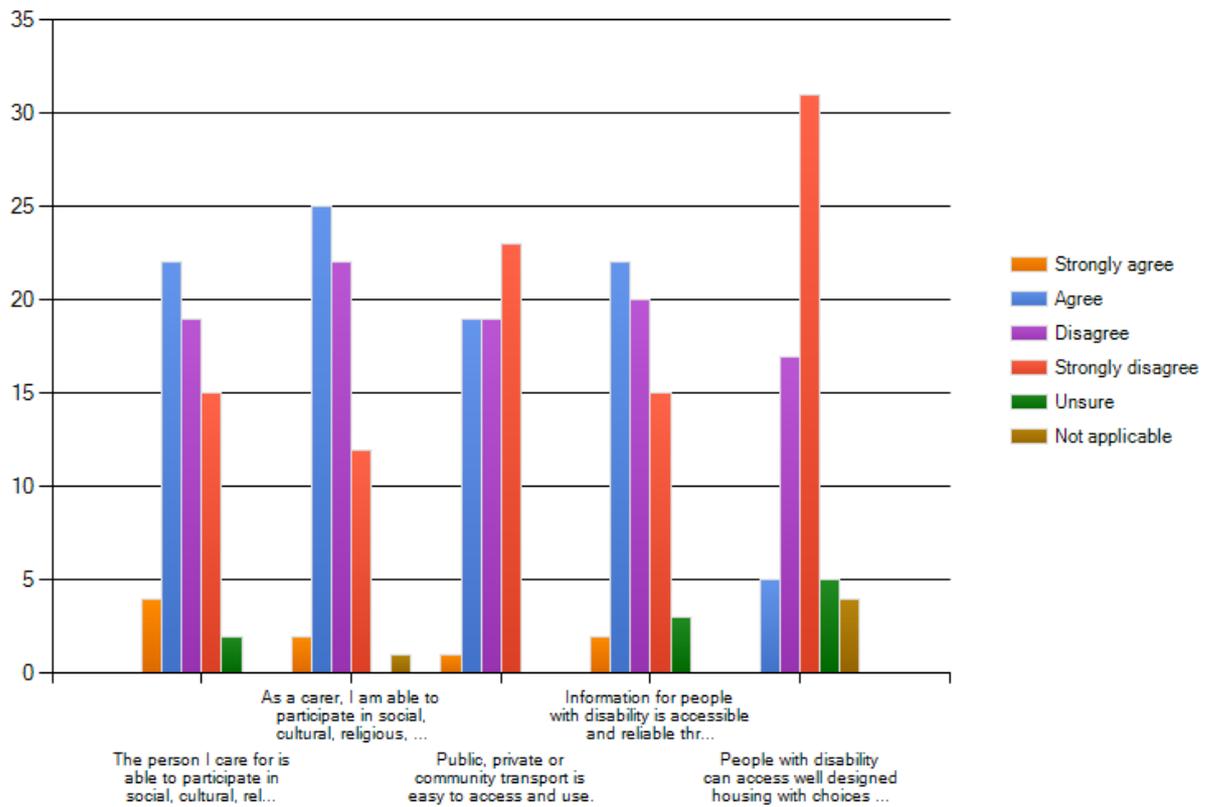
Not applicable 4 (6.5%)

Count 62

2.6 Difficulties carers have noticed for people with disability being included in the activities of their community (refer to Appendix: Open-ended responses).

2.7 What carers think Government, organisation or other groups could do to reduce barriers for people with disability being included in the activities of their community (refer to Appendix: Open-ended responses).

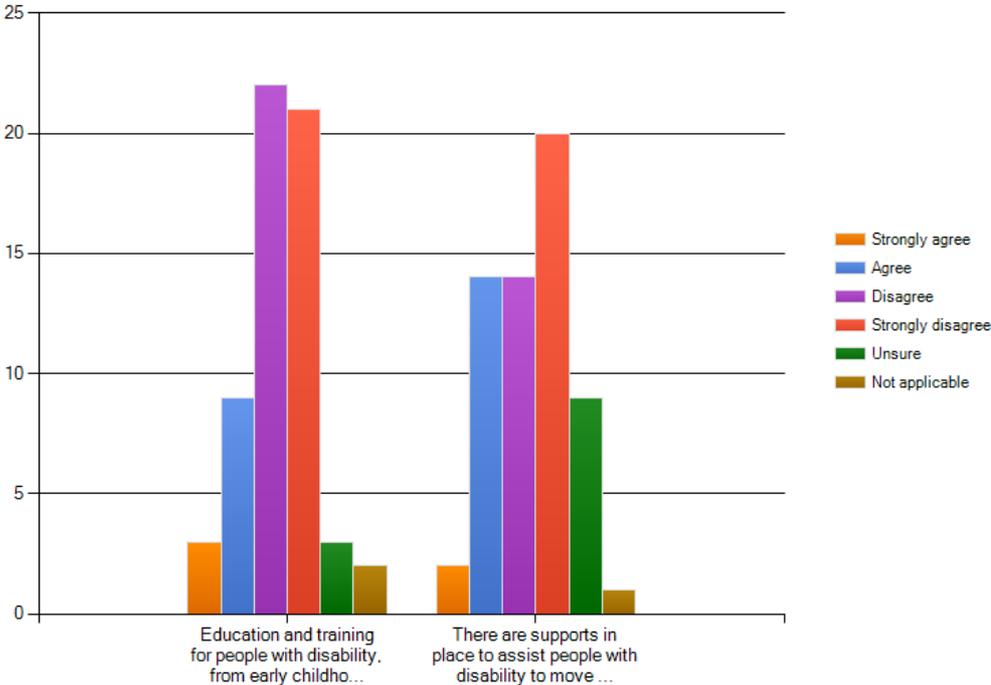
The following questions are about how people with disability are included in the community and can participate in activities. Please respond based on your own experience.



### Section 3: Questions about learning and skills development for people with disability

- 3.1 Education and training for people with disability, from early childhood to adulthood, is accessible and high-quality.
- Strongly agree 3 (5.0%)  
Agree 9 (15.0%)  
Disagree 22 (36.7%)  
Strongly disagree 21 (35.0%)  
Unsure 3 (5.0%)  
Not applicable 2 (3.3%)  
Count 60
- 3.2 There are supports in place to assist people with disability to move from school to further education, training or employment.
- Strongly agree 2 (3.3%)  
Agree 14 (23.3%)  
Disagree 14 (23.3%)  
Strongly disagree 20 (33.3%)  
Unsure 9 (15.0%)  
Not applicable 1 (1.7%)  
Count 60
- 3.3 Difficulties carers have noticed for people with disability in accessing and engaging with learning and skills development (refer to Appendix: Open-ended responses).
- 3.4 What carers think Government, organisations or other groups could do to reduce barriers for people with disability to access and engage with learning and skill development (refer to Appendix: Open-ended responses).

The following questions are about learning and skills development for people with disability. Please respond based on your own experience.



#### Section 4: Questions about financial security for people disability, their families and carers

4.1 There are opportunities for people with disability to find employment or establish their own businesses.

Strongly agree 0 (0.0%)

Agree 9 (15.5%)

Disagree 9 (15.5%)

Strongly disagree 22 (37.9%)

Unsure 14 (24.1%)

Not applicable 4 (6.9%)

Count 58

4.2 Employers are aware of the benefits of employing people with disability.

Strongly agree 0 (0.0%)

Agree 4 (6.9%)

Disagree 12 (20.7%)

Strongly disagree 25 (43.1%)

Unsure 16 (27.6%)

Not applicable 1 (1.7%)

Count 58

4.3 Housing is affordable and secure in terms of tenure for people with disability - the conditions and rights they have to occupy their accommodation.

Strongly agree 0 (0.0%)

Agree 2 (3.4%)

Disagree 7 (12.1%)

Strongly disagree 30 (51.7%)

Unsure 14 (24.1%)

Not applicable 5 (8.6%)

Count 58

4.4 Income support and tax systems provide an adequate standard of living for people with disability, their families or carers.

Strongly agree 0 (0.0%)

Agree 4 (6.9%)

Disagree 12 (20.7%)

Strongly disagree 36 (62.1%)

Unsure 4 (6.9%)

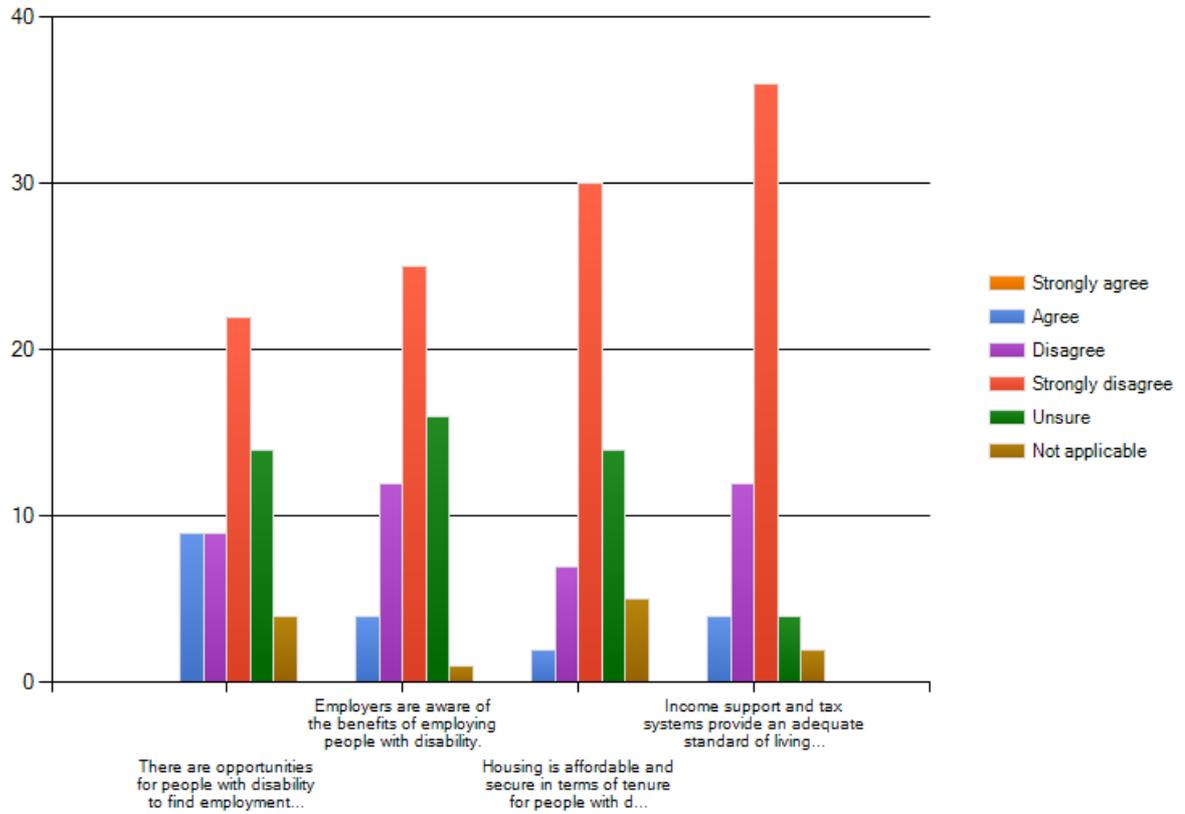
Not applicable 2 (3.4%)

Count 58

4.5 Difficulties carers have noticed people with disability experience with financial security (refer to Appendix: Open-ended responses).

4.6 What carers think Government, organisations or other groups could do to improve the financial security of people with disability (refer to Appendix: Open-ended responses).

The following questions are about financial security for people with disability. Please respond based on your own experience.



## Section 5: Questions about health services for people with disability

5.1 Health service providers (hospitals, general practices, specialist services, allied health, dental, mental health, and ambulance services) meet the needs of people with disability.

Strongly agree 2 (3.6%)

Agree 22 (39.3%)

Disagree 16 (28.6%)

Strongly disagree 15 (26.8%)

Unsure 1 (1.8%)

Not applicable 0 (0.0%)

Count 56

5.2 Health Services for people with disability are readily available.

Strongly agree 2 (3.6%)

Agree 18 (32.1%)

Disagree 20 (35.7%)

Strongly disagree 15 (26.8%)

Unsure 1 (1.8%)

Not applicable 0 (0.0%)

Count 56

5.3 Health services for people with disability are preventative or have an early intervention focus (for example treatment at a certain time can improve a condition or prevent it from worsening).

Strongly agree 4 (7.1%)

Agree 19 (33.9%)

Disagree 16 (28.6%)

Strongly disagree 15 (26.8%)

Unsure 2 (3.6%)

Not applicable 0 (0.0%)

Count 56

5.4 Health services allow people with disability to choose their treatment or to be involved in the planning of their services.

Strongly agree 1 (1.8%)

Agree 12 (21.4%)

Disagree 19 (33.9%)

Strongly disagree 15 (26.8%)

Unsure 8 (14.3%)

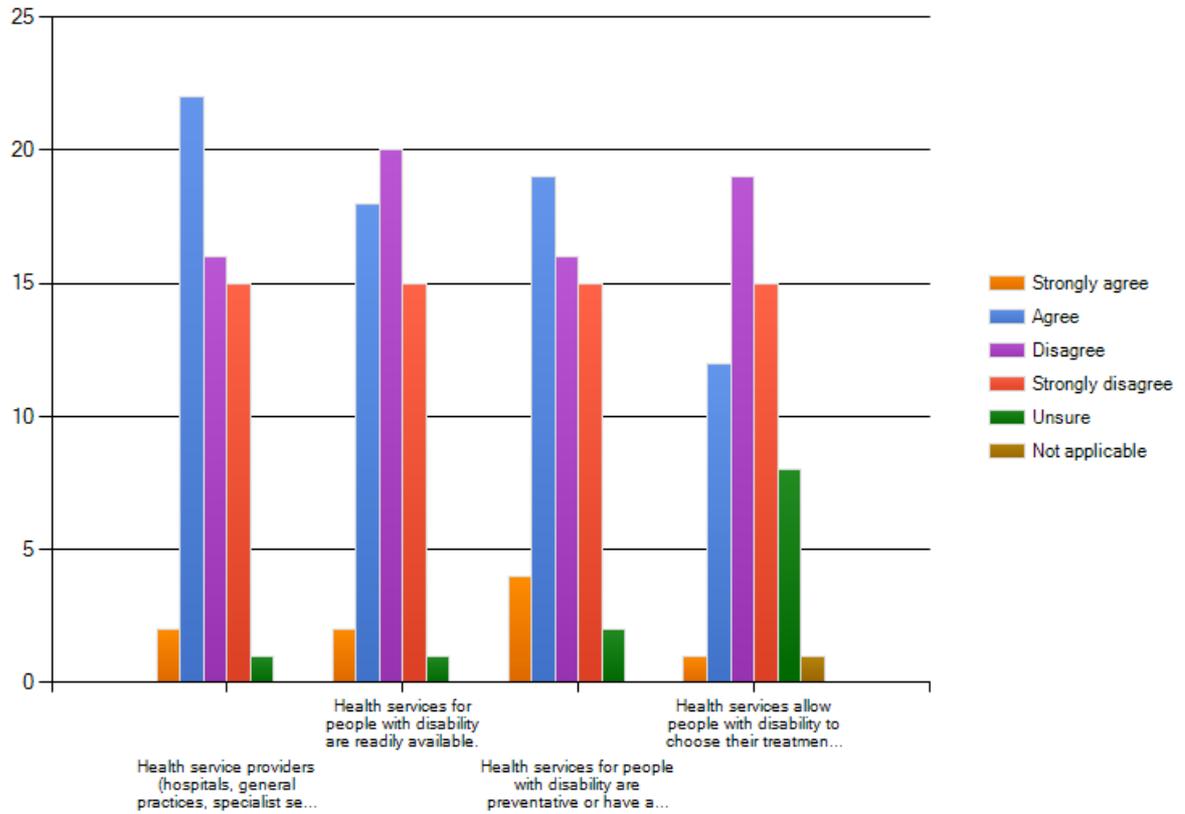
Not applicable 1 (1.8%)

Count 56

5.5 Difficulties carers have noticed people with disability have in accessing and using health services (refer to Appendix: Open-ended responses).

5.6 What carers think Government, organisations or other groups could do to improve access and use of health services by people with disability (refer to Appendix: Open-ended responses).

The following questions are about health services for people with disability.  
Please respond based on your own experience.



## Section 6: Questions about personal support services and community services for people with disability

6.1 Personal support services (for example paid support workers) and community services for people with disability respond to their particular needs and circumstances, even when these might be complex.

Strongly agree 2 (3.6%)

Agree 9 (16.1%)

Disagree 21 (37.5%)

Strongly disagree 15 (26.8%)

Unsure 5 (8.9%)

Not applicable 4 (7.1%)

Count 56

6.2 Personal support services and community services for people with disability take into account their personal preferences and maximise opportunities for independence.

Strongly agree 1 (1.8%)

Agree 14 (25.0%)

Disagree 17 (30.4%)

Strongly disagree 15 (26.8%)

Unsure 7 (12.5%)

Not applicable 2 (3.6%)

Count 56

6.3 Personal support services and community services include families and carers of people with disability.

Strongly agree 2 (3.6%)

Agree 12 (21.4%)

Disagree 17 (30.4%)

Strongly disagree 16 (28.6%)

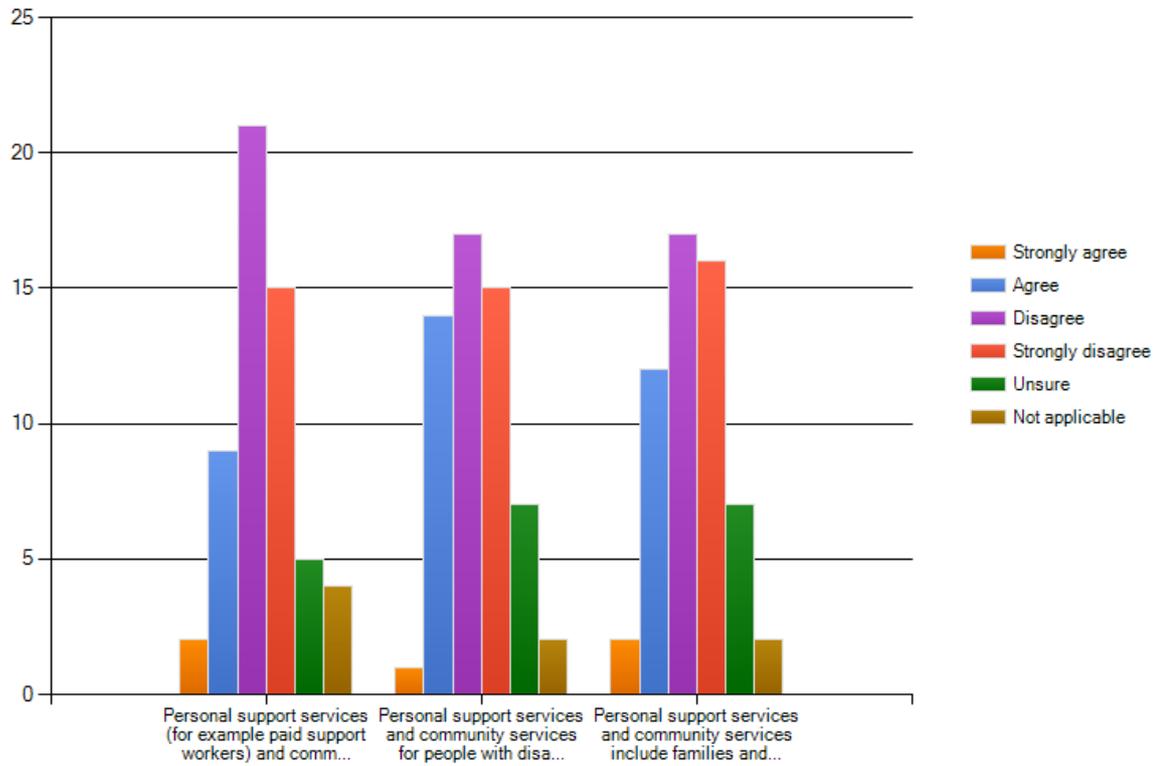
Unsure 7 (12.5%)

Not applicable 2 (3.6%)

Count 56

- 6.4 Difficulties carers have noticed people with disability have in accessing and using personal support services and community services (refer to Appendix: Open-ended responses).
- 6.5 What carers think Government, organisations or other groups can do to improve access and use of personal support services and community services by people with disability (refer to Appendix: Open-ended responses).

The following questions are about personal support services and community services for people with disability. Please respond based on your own experience.



## Section 7: Questions about rights and justice for people with disability

7.1 People with disability can express their concerns or make suggestions to improve their rights and access to justice.

Strongly agree 1 (1.8%)

Agree 15 (27.3%)

Disagree 14 (25.5%)

Strongly disagree 16 (29.1%)

Unsure 7 (12.7%)

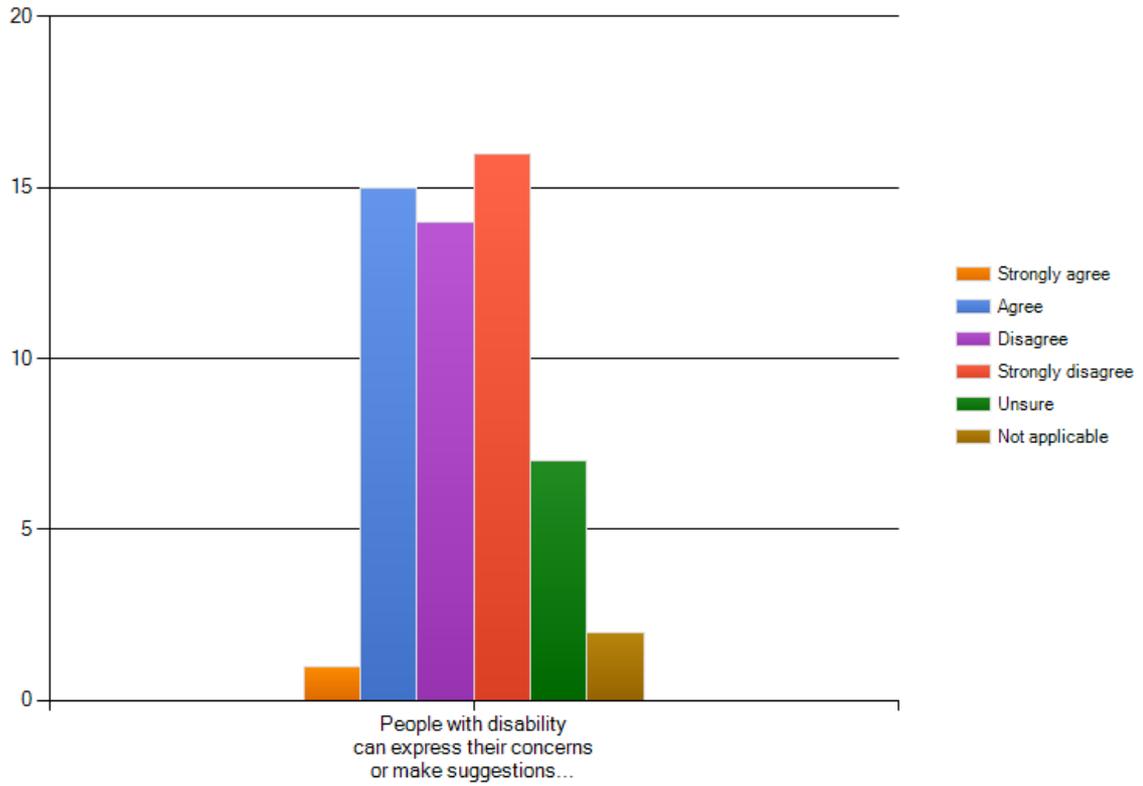
Not applicable 2 (3.6%)

Count 55

7.2 Difficulties carers have noticed people with disability have with their rights and access to justice (refer to Appendix: Open-ended responses).

7.3 What carers think Government, organisations or other groups could do to improve the rights and access to justice by people with disability (refer to Appendix: Open-ended responses).

The following question is about rights and justice for people with disability.  
Please respond based on your own experience.



## Section 8: Questions about the National Disability Strategy

8.1 Are you aware of the National Disability Strategy?

Yes 29 (54.7%)

No 24 (45.3%)

Count

8.2 The areas of the National Disability Strategy carers think seem to be working well or not so well (refer to Appendix: Open-ended responses).

8.3 Since 2010 (when the National Disability was introduced) the general public have a more positive attitude towards people with disability in the community.

Strongly agree 1 (1.9%)

Agree 10 (18.9%)

Disagree 16 (30.2%)

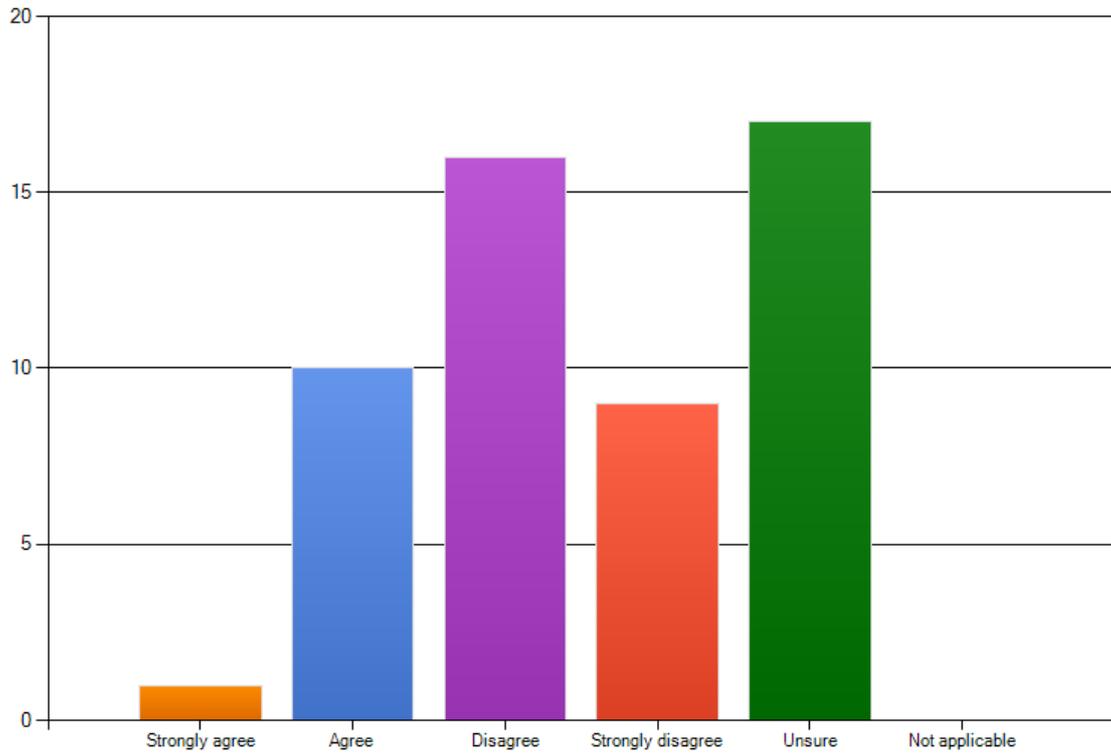
Strongly disagree 9 (17.0%)

Unsure 17 (32.1%)

Not applicable 0 (0.0%)

Count 53

Since 2010 (when the National Disability Strategy was introduced) the general public have a more positive attitude towards people with disability in the community.



- 8.4 What carers think Government, organisations or other groups could do to be able to influence more open attitudes in the community towards people with disability (refer to Appendix: Open-ended responses).
- 8.5 Additional comments carers have made about the National Disability Strategy (refer to Appendix: Open-ended responses).

## Appendix: Open-ended responses

### Section 1 – No open-ended responses

### Section 2: Questions about how people with disability are included in the community and can participate in activities

#### Summary

<i>Working well</i>	<i>Not working well</i>	<i>Suggestions for improvements</i>
<ul style="list-style-type: none"> <li>• Accessibility of the physical environment (e.g. wheelchair access) in certain areas is good.</li> </ul>	<ul style="list-style-type: none"> <li>• Accessibility of the physical environment (e.g. wheelchair access) in certain areas is poor.</li> <li>• Sporting groups lacking experience dealing with people with disability.</li> <li>• Lack of opportunities for friendship for people with disability.</li> <li>• Separation of some people with disability rather than including people in mainstream life.</li> <li>• Lack of after-school/school holiday activities for children with disability.</li> </ul>	<ul style="list-style-type: none"> <li>• Better accessibility of the physical environment/public areas (e.g. footpaths, ramps/lifts, toilets, beach access) especially in locations outside of major cities.</li> <li>• Better physical accessibility to services (e.g. medical centres).</li> <li>• Training taxi drivers to better service people with disability.</li> <li>• A greater number of maxi taxis/disability taxis.</li> <li>• Better signage in public transport for people with hearing impairment.</li> <li>• Community education/public awareness campaigns about different types of disability and disability issues.</li> <li>• Disability champions to reduce the isolation experienced by people with disability.</li> </ul>

2.6 Difficulties carers have noticed for people with disability being included in the activities of their community.

1. *Carer gets tired and overwhelmed with all household and financial responsibilities. Takes lots of energy to motivate disabled to participate in community events, and to carry through.*
2. *Lack of friends.*
3. *Wheelchair access around Albany city is still very poor. Often the ramps are too steep and even have a small step at the end. There is NO access to beaches. While 2 beach wheelchairs are housed at Emu Point and Middleton Beach, they are under lock and key and often the people who are meant to have the key don't and there are no easy access ramps from sand to the water, grass to the water. Given the number of prams and wheelchairs and elderly people using wheelie walking devices, physical access to places would be far more inclusive. Recently a popular café on Stirling Terrace changed to automatic opening door, replaced a step with a ramp and installed a toilet for wheelchair access. After years of struggling to enjoy this facility, we will now frequent it with family and friends :)*
4. *Calling up sporting group to ask about joining was given the no due to my friends little boy having high functioning autism and global delays, as "they did not have any experience dealing with this".*
5. *There is a MAJOR LACK OF HOUSING to put them in to the community. Many are isolated, especially in rural areas and so in that way they are not able to be close by where there is access to more things Also they are not able to fit in with the "norm". There is not enough SUPPORT given to encourage or make things happen. Information and Competent Support. There is a fear of public transport with these individuals because they are singled out by others in the so called "norm" picking on them, bullying them , singling them out purposefully, getting money off them, taking advantage of the less fortunate or intellectually challenged is quite a deterrent for anyone with a disability to travel on public transport. Access to public transport is somewhat available but not happening because of fear of using it and for the long distances. They may have trouble and the struggles and anxieties involved with it. I have not seen any private transport options. There are definitely no good HOUSING options. This is The BIGGEST PROBLEM for people with disabilities that are not elderly and have nowhere to go. The public housing is too long a wait. There are not enough options for it either. MORE HOUSING is needed. There is nothing available except for old people's homes for those needing support. I have two sons who have nowhere to live, creating more problems and anxiety and depression. No support for them and if their name does come up in the too many years it takes to come up also then they will not have any options as to where*

*they can live either. This is disgraceful. There are those with autism, schizophrenia and many other mental health conditions, those with physical disabilities. Why are they not all catered for!!*

- 6. Transport is one of the biggest problems for us, public transport is not reliable enough and it takes 3 times as long to get somewhere than it would by car. My daughter lives in a regional area, not within walking distance of public transport but being her driver is not considered important enough for me to get carers assistance, once she was able to handle ADL's I no longer qualified for assistance. However I still am unable to go back to work as I am her transport. If I did not drive her to every appointment or social event or therapy she would sit home and rot. My daughter is now involved in a small way in her rehab, this has taken 2years to access.*
- 7. Cost of transport to recreational activities makes it difficult to participate on a regular basis. Cannot attend without family transport being available. Recreational activities are often organised by volunteers, often students. Continuity of programs can be difficult.*
- 8. Not enough public disabled toilets, not enough transportation or parking, inaccessible shops and buildings.*
- 9. I'm profoundly hearing impaired (not deaf). My 16 year old has Asperger's, Sensory Processing, Anxiety and other co-morbid. We are in a horrible Qld housing place - the concrete floors are disgusting. Housing refuse to assist with cost of putting vinyl on the concrete to make it a little nicer & it's a very small 2 bedroom townhouse. I'm home-schooling my daughter here. Education Qld do not support children with Asperger's etc. Truly disgusted.*
- 10. We have a focus on special things for special people instead of including people in mainstream life. Bowling anyone?*
- 11. As my daughter is on the Autism spectrum, she often chooses not to participate.*
- 12. Children with intellectual impairment do not have an easy time finding activities that are suitable.*
- 13. Judgement from others in the community has isolated families with special needs. Families are opting to stay at home. If we want inclusive activities we have to organise and arrange them.*
- 14. We have a child with autism and an intellectual disability and it is almost impossible for us to do anything within our local community unless it is a specific event that has been organised through a disability awareness group who have taken into account children's needs. We tend to only do*

*things that have been organised through the Geelong autism groups as people are far more tolerant and understanding.*

15. *Difficulty in sourcing truly meaningful information*
16. *A lack of community understanding of people experiencing psychotic symptoms can lead to negative and hurtful reactions towards a person with mental illness. This often increases loneliness and isolation for a person with a mental illness. Consequently, dependency on family increases.*
17. *The person I care for has a mental illness. There is a lack of social activities that are suitable for her.*
18. *My son has ASD-Autism Spectrum Disorder. Many of the community activities such as social, recreational or sporting activities especially during school holiday are mostly tailored to Neuro Typical children. These outings can get quite full packed with people or families, with many sensory inputs such as loud noises or sounds from speakers, other children or people, lightings, etc. which can be overwhelming for children with ASD who usually have sensory sensitivity or issues. This could trigger overwhelming sense which could lead to tantrum or meltdown not because they are naughty or misbehaved but due to their sensory issues. Community or people who don't understand also judge harshly. They could show more tolerance or understanding and acceptance towards us.*
19. *Physical access is of course paramount, but for people with 'invisible' disability such as my son - who has high functioning autism, the barriers have a lot to do with community attitudes and assumptions. He has two sets of barriers in fact - he is not disabled enough to qualify for funding or services, yet he doesn't fit neatly into mainstream education or recreation either. This makes him very socially isolated.*
20. *Insufficient disabled parking spaces - and poorly designed disabled parking spaces. Steps into shops, eating and entertainment venues (need ramp access). Aphasia is virtually an invisible disability - and needs further education, research and resources to improve the life of those living with aphasia, and their families and carers.*
21. *I think my biggest difficulty is that my children have an "unseen" disability (all ASD and all high functioning) and as such, people tend to overlook that they may have just as many problems as a child with a "seen" disability. An example of this is with sports. My girls want to play netball but they tend to lose focus when the ball is up the other end. Activities such as gymnastics and dance*

*would suit them well, but most of these are down in Midland or Perth and who can afford the cost when one of us had to give up work to care for them?*

22. *I wanted to attend the Cara picnic in Woodville but it cost \$100.00 each way in a taxi for wheelchair.*
23. *This depends greatly on the type of disability, you can't have a one size fits all approach. One major problem we have is the assumption that everyone wants to be involved in groups or activities that may be very sensory or neurologically overstimulating. It is extremely difficult to be included when this is the case.*
24. *Individuals with high support needs always require assistance. It is tough on unpaid carers. It became evident to me when my daughter was young that in order for her to be able to reach her potential I would have to give up my personal goals and aspirations.*
25. *My daughter can't go anywhere as where I live in Coomera no transport. I contacted trans cord was told can't help. From being able to go and do things go to centres here in Coomera she sits alone does nothing also where she goes 1 day a week have the time they don't know what they are doing QUEENSLAND HAS THE WORST SET UP FOR PEOPLE WITH DISABILITY COMPARED TO OTHER STATES THEY ARE 20 YEARS BEHIND.*
26. *Lack of accessibility. Lack of Public/Community Transport options.*
27. *Understanding, lack of respect, hidden disabilities such as mental illness and Autism misread and misunderstood.*
28. *Attitude of others.*
29. *Cannot get assistance to go swimming. In my situation it would be good for both of us. Some single adults with disabilities needing additional assistance. Transport assistance for themselves & their children. Including where children identify as a Young Carer.*
30. *My son has a communication disorder. This tends to impact everything he/we try to do.*
31. *It is extremely hard to access the community without the assistance of a second carer, and since we are still waiting on funding I am unsure when we will be able to participate in anything like this for my son anytime soon.*

2.7 What carers think Government, organisation or other groups could do to reduce barriers for people with disability being included in the activities of their community.

1. *Education.*
2. *Help them to get paid work and support them all the way with hands on help.*
3. *Not sure.*
4. *Physical environment still seems to be a barrier in regional centres. We go to Perth and everything in public seems to be "inclusive" of wheelchair access. Government is very good at making new buildings and businesses comply with standards for wheelchair access. However, there are many public facilities, utilities, etc. Footpaths being a classic example, where there needs to be refurbishments from mistakes of the past.*
5. *Provide trained professionals to assist as one-on-one carers if needed.*
6. *By providing MORE ACCESSIBLE HOUSING. Reducing waiting lists for it - this will give them more options to get somewhere into a suitable community where they are close by to services. Whereas they will also learn some independence and feel more confident to be a part of it. By giving more ongoing support via support workers to those with disabilities and also under the mental health umbrella as well. The DHS criteria for people with disabilities needs looking at!! Case management is necessary for people with intellectual and/or disabilities of all kinds. The DHS criteria to give support are ridiculous because they do not accept anyone who has not got access to a diagnosis over 18. My son was diagnosed at 18 and the reports went AWOL He has a noticeable intellectual disability as well as schizophrenia. Some people slip through the cracks for lack of professional help or incompetence from them to work it out. I have a son who has struggled to get a support worker throughout his life! Without one they go nowhere and this is where it can lead to frustration for them and some may end up left alone and end up with suicidal tendencies or crime which could be avoided if they were supported properly and with professionals that know how to transition them into the community. Also the community need to be educated better. CARERS NEED MORE HELP. Education and direction to the right people. It is a massive maze out there. Things are hidden from the public eye and there are things that are not told about available. Well I haven't found much unfortunately but now and then suddenly after years of searching for answers I may accidently stumble on some info. In the overwhelming task of taking care of people, family members that is, it is hard for Carers to spend hours looking for information they are on demand 24/7 and they do not have much energy left by the end of the day. Their heads are full of trying to sort out without help how can we get through this. How can I*

*find helpers to support him? Hence more competent support is needed. The support people need to be educated to be able to help whether they are mentors, helping to rehabilitate, helping to help families as well. Doctors need to be informed of all the possible options for everyone properly. I can't believe the lack of support out there the lack of housing options it's disgraceful.*

- 7. Provide FREE transport and work out some scheme where the main carer can claim for fuel or some such, being able to get around easily is key to good outcomes, you can die of frustration trying to get anywhere in Vic. Maybe part of the new system could include a fleet of taxi's with properly trained drivers (maybe just with a Cert 111 in HACCC) to pick people up regularly, not just once a month.*
- 8. Paid workers. Funds for transport.*
- 9. Build better toilets and improve old building accessibility, more public/community transport for wheelchairs.*
- 10. Reduce the red-tape make it easier to access services in particular with respite services. Speed up the process. Provide more funding.*
- 11. SIGNAGE for hearing impaired people. We can't HEAR what transport etc. are saying over microphones/speaker systems. Public transport is terrible - buses don't meet trains - wait 30+ minutes in the hot sun (no shelters) for a connecting bus/train. Housing ... what can I say. Put us in a clean, new place where there are NO smokers, drug addicts or loud drunks. Please! Education - leave us alone to decide how our children need to learn and our kids will learn better - much better than the education system allows. Truly.*
- 12. Have ramps or lifts where there are steps. More footpaths with sloped curbs. More ACROD parking bays at shopping Centres etc. More accessible beaches with a carpet that can be rolled out when necessary. More Maxi Taxis with less waiting time (we were left stranded in the rain for several hours one day). All Medical Centres should be easily accessible. (My wife's neurologist's rooms have steps at the entrance!). Counters in shops etc. should have one part lower. Petrol stations should cater more for people who can't get out of their cars to get petrol and then pay.*
- 13. Fund disabled persons and self-advocacy groups. Invest in the mainstream. Stop providing bandaid solutions like massages for Carers who have collapsed with exhaustion, support the person properly. Invest in the NDIS.*

14. *Make funding available to help. My daughter chooses not to respond to my efforts to teach her, but will sometimes respond with great enthusiasm to another person. With only 12% getting ANY funding, how can any but the most severe get help? (That figure was from a DSQ worker).*
15. *The 'Get Started ' program is helpful in Qld, it would be good to have additional funds for this program.*
16. *Give us more inclusive events or support families that are arranging and organising this inclusive events. Families with special needs struggle during the school holidays, adding more pressure and stress*
17. *More tolerance needed and education.*
18. *Connect people with disabilities to organisations (champions) at the points of diagnosis to help them on the journey and reduce isolation.*
19. *In the case people with severe, chronic mental illness, ongoing support in dealing with paranoia and other psychotic symptoms. For successful independent living, home help with cleaning and maintenance, encouragement and support in scheduling and accessing activities based on personal interests.*
20. *Make things free or affordable, offer variety and choice as not everyone with a disability is the same or is interested in the same activities. Advertise things as widely as possible to ensure people know what's out there.*
21. *Be realistic - they don't all come in the same box.*
22. *Government or organisations could increase awareness & tolerance by creating public campaign or providing support services as well as facilities to accommodate people with special needs.*
23. *It's important that they have understanding of the wide variety of disabilities and how to work with people who have them. A good example is Glen Eira Sports and Aquatic Centre - a good mix of physical access, programs for people with disability and programs for everyone - including people with disability.*
24. *Provide adequate disabled parking spaces. Provide ramp access to all buildings. Provide adequate toilet facilities for people with disabilities. Recognise aphasia as a serious disability, and assist people with aphasia to participate fully in their community.*

25. *Perhaps if there were more choice for carers to access in country towns that didn't just involve team sports and that these choices were offered some kind of financial assistance. We have the option to get the kids into all kinds of team sports where we can get some monetary help but no individual ones as far as I have found.*
26. *Have more disability friendly venues and transport.*
27. *By recognising that there are many different types of disability, many of which aren't obvious. Allowing people to have individual needs met, or at least acknowledging that there are multiple individual needs. And programming and funding many different options and ways to fulfil needs would be a good start. The individual and possibly their carers would have a much better idea of what is needed than government etc. A bottom up approach!*
28. *Provide support staff at activities.*
29. *GET BETTER TRANSPORT AND HAVE MORE CENTERS IN QUEENSLAND. QUEENSLANDS A JOKE ALL SO DSQ ONLY HELP YOU FOR A YEAR THEN YOU'RE ON YOUR OWN.*
30. *Mandate accessibility. Invest in Public Transport infrastructure. Provide more funded individual support for people with disability so they can access activities.*
31. *Smaller gatherings, include able bodied people as well as disabled.*
32. *Education.*
33. *Provide Basics for these people/families - fund COMMUNITY TRANSPORT to take children of ADULTS with a disability/chronic illness to and from school. This will provide SAFE, stable transport. Every child has a right to an education. They also needed assistance to get there. Community transport currently provide assistance for social inclusion/sports & rec/medical appts., but not funded for school transport. Too much focus is placed on social inclusion, recreational activities at times. And the BASICS for families are overlooked. Most other Volunteer organisations currently in place are not suitable - mainly there to assist adults get to/from medical appts. & providing \$\$ to families for taxis is ridiculous when the child may be 4-5yrs old. And therefore does not cater for children who are vulnerable. Please fund Community Transport to take these children to/from school. This will reduce stress on the family units, which will enable all members to have better opportunities to engage positively with the community.*

34. *Greater support in accessing the community, sporting groups and clubs so that as parents/carers we are not the only ones having to assist. It is difficult to constantly have to manage both my son's behaviour/anxiety while in social settings but it becomes more complicated having to also manage other people's reaction to him.*
35. *Making it easier to access funding packages and things at an affordable cost rather than being on a waiting list for years before anything assistance being offered to access the community and to participate in the community. After four and a half years of waiting for services and still waiting my son is deteriorating and will find it harder for us to find activities he will be able to participate in as he loses more and more movement.*

### Section 3: Questions about learning and skills development for people with disability

#### Summary

<i>Working well</i>	<i>Not working well</i>	<i>Suggestions for improvements</i>
<ul style="list-style-type: none"> <li>• TAFE/university access courses for people with disability.</li> <li>• Education Assistants/Teachers Aids.</li> </ul>	<ul style="list-style-type: none"> <li>• Transitioning from school to post-school life (e.g. further education or training, work, or other pursuits for young adults or adults with a disability).</li> <li>• Difficulties with transport to and from educational facilities, particularly in areas outside of major cities.</li> <li>• Lack of parking for people with disability at some education/training institutes.</li> <li>• Inadequate mobility allowance in areas outside of major cities.</li> <li>• Lack of flexibility of some disability employment agencies.</li> <li>• Lack of support for children and young people with an Autistic Spectrum Disorder.</li> <li>• Some schools putting pressure on parents/carers of young people with a disability to volunteer their time, procedures that might single out or further stigmatise students with disability.</li> </ul>	<ul style="list-style-type: none"> <li>• More supports put in place in the period of transitioning from school to post-school life (e.g. training opportunities for people with disability that leads to employment, higher education access courses).</li> <li>• Greater choices in the mode of learning for people with disability (e.g. online courses).</li> <li>• Increased funding for Education Assistants/Teachers Aids.</li> <li>• Use of electronic devices such as laptops, iPads, e-books for people with certain types of disability rather than hardcopy materials and books.</li> <li>• Disability training for teachers in mainstream schools.</li> </ul>

3.3 Difficulties carers have noticed for people with disability in accessing and engaging with learning and skills development.

1. *There is a limited choice for disabled people and costs are high. Just the transport costs to get them to facilities is very high or we have to spend every day driving them to and from places. This gets very costly and tiring for carers. The variety of courses available is very limited and because of the huge drop in funding to TAFE classes are limited, crowded and under staffed. TAFE Access courses are wonderful for helping disabled people learn new things and helps them greatly to access possible employment.*
2. *I acknowledge that there are supports in place to assist people with disability to move from school to employment but have seen the situation where the employer (local authority) refused to accept the helper.*
3. *There is a strong need for more understanding and training.*
4. *Access to quality education with suitable support has been very good in our experience. Could have done with greater assistance to understand the options for navigating a 'creative' route through upper secondary school though.*
5. *It took many years to access any services. Years of searching to find there was a lack of continuity and support.*
6. *Just not enough staff to go around, takes too long to access services and finding them is a whole different problem, there are too many little groups trying to help, most of the funding seems to be spent managing all these different groups rather than actually helping their clients. I have spent hours and hours on the phone and end up talking to heaps of different places offering the same or similar services then I spend further hours and hours filling out forms only to find we only qualify for a hand full of things or that the funding has been cut ... .just last week grrr.*
7. *Access to the buildings providing the education costing too much.*
8. *My daughter has Asperger's, SPD, Anxiety and other co-morbids. Schools/Education departments have NO idea how to support our kids. Or rather, they misuse the funding for our kids. I home-school now to avoid all that crap.*
9. *Lack of ramps. More self-opening doors. More aids to help deaf and blind people.*

10. *No funding for transport especially in regional and remote areas, no funding beyond school for personal care at uni or TAFE.*
11. *Once my autistic son turns 7 I have no more funding and other than 20 free OT sessions. I believe we are on our own and have to self-fund any therapies. I work but am limited with options and my husband has been unwell for over a year making me the main carer and provider.*
12. *If you don't have a package there is NO help! Calls are not returned.*
13. *The supports are very inadequate especially for children with intellectual impairment making the transition from school to post school life.*
14. *There isn't much on offer regarding training for disability for adults, most cases they are left unsupported. As for Schools children with disabilities are being suspended and excluded every day because of untrained and inexperienced staff, leaving disability children with no education being taught and a negative experience.*
15. *My husband engaged with disability employment agency appointed through Centrelink who had no flexibility in their process. That is was wanting to take him on the journey of preparing a resume when my husband already had one. Turnover of employees in the employment agency also meant it wasn't progressing anywhere. Every time he came home he was demoralised and his confidence had depleted even further.*
16. *There is a lack of flexibility in our area. This includes the types of training and education offered, as well as delivery methods. For example there is basically nothing available locally (e.g. at our TAFE) online or flexible delivery.*
17. *My son has speech & language delay. This has impacted in his language & comprehension as well as understanding. Hence, it impacts in his learning & skills development. He could go to kindergarten but whether he could understand fully what will be tough over there is another question. This will be applicable to prep school and primary school as well later on down the track. Especially with mainstream primary school and high school. Sometimes due to IQ level that is high enough, these ASD children could go to main stream school & they are not eligible to go to a specialised school however they are still struggling and needs extra attention and support for them to be able to learn, grow, and thrive within the main stream school environment. They need extra support in helping them communicate and socialise with others. The lack of support from government and school in this area is frustrating and makes it a lot more difficult for family like us who are already challenged in dealing with this ASD.*

18. *My son goes to mainstream school and I can't tell you how many times teachers or other parents say to me, "Oh, but he seems so normal" when I tell them about the meltdowns he has at the end of the day or when he's not coping with homework or maths concepts. There is not a lot of appreciation in the general school community of what it means to be a student with high functioning autism. His school has some teachers with a special interest in autism, but there is nothing systematic in place.*
19. *Our local secondary college doesn't provide a parking space for people with disabilities, for a start.*
20. *Whilst we have support from the Autism society and our school which is wonderful, they can only do so much. Especially when we are losing all important Education Assistants.*
21. *My son has to travel to Birdwood for training in mechanics. I either have to drop him off 2hrs early, find someone else to take him or take time off work.*
22. *There are very few organisations who offer courses for someone with an intellectual disability. Tafe used to do this very well. I now wouldn't bother trying to access this for my daughter. What they offered about 5 years ago for her was almost nothing. I tried again about 2 years ago and was told there was nothing. My daughter is a very high functioning person with an intellectual disability, and wouldn't need a lot of support. There seemed to be an enormous amount of 'waffle' (unnecessary talk and paperwork) involved in what she was taught. I had a lot to do with Tafe years ago, and they used to be for everyone. Very inclusive. I know this is now not the case.*
23. *Huge amount of difficulties in people understanding the nature of the disability (or even that there is one at all) and what is really required to help the person engage in a manner that is truly workable for them rather than just a way to fit them into a system.*
24. *Living in a rural area means that we have to travel long distances for everything yet the mobility allowance is the same as for people in the cities. Also funding packages don't go nearly as far in the country because of costs of travel with carers and the extra time which has to be paid in wages.*
25. *FUNNY THERE'S VERY LITTLE.*
26. *Lack of individual support funding limits opportunity to attend learning & skills development.*

27. *Teachers' attitudes and expectations. Don't necessarily extend people into the zone of proximal development. Can have the attitude we don't expect anything so why bother.*
28. *There is a lot of early intervention up to the age of six and then no more help until the transition from high school to other (uni or work) if a child doesn't get diagnosed or a disability until after 6 there is very little support or funding available.*
29. *Need more support.*
30. *When attempting to enrol my son in a Prep program in a regional town in Qld I was not offered full days and was told it might be necessary for me to volunteer my personal time as a full time teacher aide at the school to free up staff time. They had a human resources issue to the point where children with disabilities were put in bright vests each playtime to make them stand out from the children without disabilities and more easily tracked by staff. It was less than ideal.*
31. *My son left high school after completing year 12, once he left we had no contact with any agencies to help us as my son entered into his early adult years.*

3.4 What carers think Government, organisations or other groups could do to reduce barriers for people with disability to access and engage with learning and skills development.

1. *Provide help with transport and more funding to TAFE and others learning facilities.*
2. *Most disabled people I have known will respond well to one on one learning & skill development. This is not available.*
3. *Total support where they can help not fog them off and no support.*
4. *I'd rather not say.*
5. *Funding for general education should NOT be cut. Mainstream, inclusive education for students with physical disabilities that may or may not be combined with Intellectual disabilities, is vital to their development in becoming a productive member of society. Cutting funds to the services provided by Education Assistants was one of the worst things to happen in proactive education for children.*
6. *Make it more available and more known. There is a lack of training there is a lack of support. And again lack of information available. There is also not enough offered. I have looked for support. My son recently managed to do some volunteer work with a view to a traineeship- the plug was pulled on him after 6months of volunteering just before he was meant to start. By the government cutting funding to the traineeships!! This is disgraceful! And they want people to work - these people are treated with total disregard!! And some of the programs available for work pay a wage to them that does not even cover their travelling to and from the venue. It's not right to discriminate against people with disabilities - many are capable they should be payed accordingly not like just because they have a disability they automatically get paid less than everyone else. Whether they work a 4 hour block or longer or 2 days or 1 day they should be paid accordingly. Not 5dollars an hour whilst everyone else gets 20!! Create some INCENTIVES and be fair... with their payment and understanding with their disability and conditions.*
7. *Clean up the mess, the paper trails and get everything under the one umbrella, a person needs a case worker that can access everything not just the services their dept. provides, so much waste of time and money.*
8. *Make every community have better facilities for education for adult disabled people.*
9. *HONESTY! Stop the misuse of funds meant for our kids! I won't go on.*

10. *Make all educational institutions wheelchair friendly by having more ramps and making each building accessible. Wider door with lower door handles and wider corridors with no clutter. Use e-books with iPad of similar. Many books are too heavy to hold for long. More computing skills taught, especially how to use the functions on a computer to help the disabled, the younger the better.*
11. *Fund personal care at tafes and fix the entitlement model and priority skills list.*
12. *Should be able to bulk bill to therapists, including physio which we need but can't afford and it does not get covered by the autism package.*
13. *Support parents by making funding available (as well as choice if funding available).*
14. *There is a need for people to have work or study options that suit their disability. Post school training options should be available based on school IEPs and provide similar hours as a school education for a period that prepares the person with a disability for employment if possible.*
15. *Give Schools more Teacher aids that have up-to-date training in these disabilities, so the children can be supported in the mainstream system. Make compulsory teachers have training and support. Disability children's suspensions should be individually monitored and strategies should be put into place to lower number of suspensions. More training for special needs adults, give employers that take on adults with disability incentives to try and keep them in employment.*
16. *Educating organisations on the positive effects of employing people with disability.*
17. *Reduce the red tape that exists. Provide a multi-pronged approach to learning and skill development e.g. online, local accessible settings.*
18. *Flexible delivery is a must. Offer a variety of ways for people to attend, including face-to-face, online, etc. Offer skills development, etc. computer skills. People who lack these basics find it very difficult to participate.*
19. *Government could provide extra support and education through funding, special aid or support worker in class rooms to help with these kids as well as providing teachers and schools with education, awareness and funding they need to support special needs children.*

20. *Schools need to engage more deeply with parents of children with high functioning autism - be proactive, don't wait for a crisis and don't expect the parent to do all the chasing, then get annoyed when they're on the phone trying to resolve something.*
21. *Provide everything that I mentioned in question 8.*
22. *Stop ripping the Education Assistants out of the school system and relying on teachers being able to deal with large class numbers AND children with special needs. They do the best they can, but they can't be everywhere at once and children NEED the one on one attention that the EA gives.*
23. *Again more accessible training and transport*
24. *Reduce red tape. If there are courses out there, make them affordable, and accessible. With self-managed packages now available, a fee is affordable but not an exorbitant one.*
25. *By learning more and being open to new paradigms of learning.*
26. *Training organisations should provide support workers free of charge to people with disabilities.*
27. *CUT ALL THIS PAPER WORK AND SEE THAT THINGS DON'T COST. SOME CENTRES CHARGE PEOPLE MORE THAN HALF THEIR PENSION JUST TO GO TO A CENTRE WHILE THE BOSSES OF CENTRES MAKE A FORTUNE NOT EVEN THE STAFF GET GOOD PAY THEY WORK ON A DAY TO DAY WHILE BOSSES NEVER EVEN GO INTO THE CENTRES MOST TIMES THIS IS BECAUSE MOST CENTRES ARE PRIVATE THEY SHOULD BE LIKE SCHOOLS FREE TO GO TOO JUST PAY FOR WHAT THEY USE BUT CENTRES FEES CAN BE AS MUCH AS \$400 A TERM AND MOST TIMES THERE'S 3 TO 5 TERMS A YEAR PLUS BUS FEES AND LUNCH DAYS OUT FEES FAR TOO MUCH.*
28. *Provide support with transport to attend, and support to access L & S development.*
29. *Employ proactive teachers how help students to be empowered.*
30. *Governments need to think outside the box, maybe funding could be for 2yrs after diagnosis, maybe there could be funding for primary and high school or maybe development funding to help children that are struggling.*
31. *Provide more support*

32. *Funding for additional staff would go a long way and for improvements in environment with such things such as good fencing. Maybe children wouldn't need to wear vests which by their very purpose are meant to identify kids as having a disability. When I asked about schools with better fencing I was told "schools aren't jails". Changing this type of attitude towards people's concerns might also be a good thing.*
  
33. *As soon as they are identified with having very high needs they need to have the correct services in place before leaving school so they can be the most successful young adult they can be within their community, instead of making them and their family feel like a burden to everyone around them, and isolating them while they wait for the services to begin.*

## Section 4: Questions about financial security for people disability, their families and carers

### Summary

<i>Working well</i>	<i>Not working well</i>	<i>Suggestions for improvements</i>
<ul style="list-style-type: none"> <li>• Carer payments acknowledged and appreciated by some respondents.</li> <li>• Home Energy Saver Scheme (HESS).</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of choice and availability of housing for people with disability.</li> <li>• Discrimination from the private rental market.</li> <li>• Inadequate income support to manage on for both people with disability and carers.</li> <li>• Eligibility criteria for carer payments.</li> <li>• Impact of caring on the person's career, income, superannuation.</li> <li>• Carers needing to withdraw superannuation in order to financially support their family member who has a disability.</li> <li>• Employers not accommodating people with different needs and abilities.</li> <li>• Lack of training available to people with disability on financial management.</li> <li>• Safety and security issues associated with public housing for people with disability who are vulnerable.</li> </ul>	<ul style="list-style-type: none"> <li>• Greater availability of affordable and accessible housing for people with disability.</li> <li>• Incentives for employers in employing carers and people with disability.</li> <li>• Introducing targets for employing people with disability in workplaces.</li> <li>• Mandatory disability action and inclusion plans for public sector employers.</li> <li>• Subsidies for utility costs.</li> </ul>

4.5 Difficulties carers have noticed people with disability experience with financial security.

1. *Housing for people with a disability is nearly impossible to find and afford. The amount of money needed to support a disabled person to live independently in their own home is huge, especially if they need carers with them 24/7.*
2. *From personal experience I can say that income support is insufficient to manage on. Withdrawing superannuation (which cannot be replenished) is the only short term solution to enable us to continue living in our home. One day the superannuation will run out. One day my disabled husband will pass away. I will then be over 60 & unable to manage financially. I will be unemployable as I have been a full time carer for so long, and too old for anyone to employ me. I also have my own health issues. Very scary.*
3. *Need for more help understanding money and savings it's hard trying to help love ones to understand their finances*
4. *There is a fair degree of sacrifice for carers of people with disability - career, 'disposable' income, holidays, etc. superannuation.*
5. *I believe it's not just disabled community struggling financially it's a lot of working class families. Utilities and living expenses continually rises but wages remain stagnant.*
6. *There is no financial security for them unless their parents are rich. Not enough support or employers wanting to employ people with disabilities. Not enough housing available. There is no security if there is no housing available. In terms of paying for housing it is not affordable if a person with a disability has to stay in supported accommodation. They have no pocket money left for other things. This is residential care which is not adequate at all. As far as public housing is concerned. They have to wait years to get housing!! I do not think income support is adequate at all my other son struggles every day to eat!!! and buy clothes. He pays rent where he is at the moment and is relying on myself and family to help supply food!*
7. *I do not qualify for a carers pension however I have had to give up work to care for my adult daughter. This is the 3rd year I have been home with no income, we are going broke, our whole family is struggling and the disability pension is not enough for someone to have any quality of life, especially when you have to pay rent to DHS (we have a DHS unit on our property and she still has to pay rent!!) and then a small fortune to travel.*

8. *Wait. There's more \$\$ out there that we don't know about? Employers and modern technology have left the hearing impaired behind - no one wants someone who can't answer the phone. A simple thing, yet so complicated/impossible for a person with a profound hearing impairment.*
9. *We are all broke. 27 out of 29 on the OECD scale. Cost of disability never noted.*
10. *Have you tried living on a disability pension? There is no security and not many options in improving your circumstances. I get the carers allowance which is certainly an acknowledgment and appreciated. The weekly amount is not much but the yearly supplement allows us to buy big things that can help our son and is appreciated.*
11. *Because I have cared for my daughter alone since she was 2 1/2, I have only done occasional casual work. Hence NO SUPER. Have to rely on Carers pension & DSP.*
12. *The Disability Support Pension does not allow a lot of freedom for recipients, options always come with a higher income from paid employment.*
13. *Families are in rental accommodation and it is not secure accommodation. Last year alone more families with disabilities had to move because the house was on the market or owner wanting to move back in. The cost of moving takes its toll financially on the families, plus the lack of privacy when open homes. The lack of funding to own your own home is next to impossible for a family with special needs because of other costs like therapist, equipment.*
14. *My friend cares for her two autistic kids and two infant daughters. She could use live in help!*
15. *My husband and I have discussed our child's future employment options which would be about zero and are both currently working our lives away trying to get ahead so we are able to set our children up ourselves. Our child will never be able to earn enough money to be able to afford to pay her own bills and food let alone buy a house.*
16. *The red tape of Government services and agencies and community perceptions.*
17. *For people with a mental illness, budgeting, especially, can be an issue. The stresses caused by financial issues often exacerbate the illness.*
18. *There is very little housing available for people with a disability in our area. What housing is available is unsupported and unaffordable. What income support is offered to people is an absolute pittance. I and my siblings supplement my mother's Disability Pension with our own*

*money because she couldn't afford to live without it. I give all of my Carer's Allowance to her and I also take money out of my own pay and give it to her, as do my siblings. If we didn't do this she couldn't eat. My mother lost her job as a direct consequence of having a disability and she has now lost the confidence to leave the house. She is a registered nurse of 35 years and was told by the employment support agency to go and find a job at the local bacon factory. Disgraceful. She lacks technology skills and needs training in computers, but that's not available here.*

19. *The cost to provide Early Intervention is enormous although the government provides funding. We still have to use a lot of our fund to access the therapies needed through private practices. If we access the government facilities, the waiting list is either a year or longer. This is not good enough.*
20. *I don't know yet - my son is only 9.*
21. *The disability and carers pensions are inadequate to cover day-to-day living and medical expenses.*
22. *After paying rent buying food and paying for carers there is no money left for outings or social interaction.*
23. *If my daughter didn't live with her family, she would not be able to support herself.*
24. *Extremely difficult to experience financial security- often you get so far behind it is very difficult to catch up let alone be able to provide options for setting up a business or paying for education. Employers often will not consider someone who has different needs. Families can be under considerable financial stress, which ultimately affects everyone involved. Costs may be higher for the disabled person.*
25. *Impossible to buy own home, yet too risky to live in public housing for vulnerable young women with disabilities.*
26. *PEOPLE WITH AUTISM OR BRAIN DAMAGE ARE LIKE CHILDREN AND WANT THINGS LIKE CHILDREN MONEY SHORT ALL THE TIME PLUS ONCE AGAIN WITH CENTRE FEES THERES NO MONEY LEFT CENTRES TAKE WHATEVER THEY WANT CONTROL WHAT CENTERS CAN CHARGE PEOPLE WITH A DISABILITY NEED WHEEL CHAIRS SPECIAL BEDS SOME NEED THE LIGHT ON SOME WILL ONLY EAT SOME FOOD SOME WASH THEIR HANDS ALL THE TIME THEY CANT TRAVEL ALONE LIKE MY DAUGHTER SHE NEEDS 24/7 CARE ALL THE TIME IN 44 YEARS ONLY HAD TWO YEARS BREAK NOW BEEN INFORMED GOING TO BE GIVEN 1 DAYS BREAK EVERY YEAR BIG DEAL.*

27. *Difficult for carers to access Carers Payment where it is required. Carers Payment is often grossly insufficient, considering they could be providing up to 20 hours of support each day! People with disability often have low income, but have higher cost of living due to additional medical and/or pharmaceutical needs to maintain their health.*
28. *If you mention disability when applying for a house especially Autism forget about being accepted into the private rental markets and public housing has to long a waiting list and when on low income who can afford to buy. Many people can't maintain a property due to disability and can tend to live in squalor and there is no support for helping people get out of squalor and maintain a property. Many people are on a rent cycle from house to household items and cash advances as well as pawning goods.*
29. *Most of the time funding is not adequate when you consider respite or carer fees, household expenses, therapy expenses, medical and pharmaceutical expenses etc. Also home assist is a joke, money is wasted on the person entering the house and saying what they will and won't do.*
30. *Lower pay rates.*
31. *DSP-From Centrelink is not sufficient funds for a single person/single person with children. No matter what town/city in Australia you live. With the cost of living today, if it is your only income source, it is a battle to survive. Because of this, most people are pushed out of private market, into long waiting lists in public system & become more dependent on welfare organisations such as Anglicare, Salvation Army etc. for assistance. Many adults with disability may have had to access/exhaust their Superannuation early, unlike other people the same age. They generally will not have the opportunity to generate/create Superannuation for 'retirement'. Exactly the same for those on Service Pension from Department of Veterans Affairs.*
32. *Because of my son requiring a house to accommodate his wheelchair, and there was none around we have had to go into a private rental and combine his disability pension and my carers pension to pay the rent each fortnight, when I went into housing commission and asked if wheelchair friendly houses were available and how do I get on the waiting list, she had told me she has not heard of any available and if there were we would be waiting for over 10 years before we may even be offered one and then it was not a guarantee.*

4.6 What carers think Government, organisations or other groups could do to improve the financial security of people with disability.

1. *Supply affordable housing so they can live as independently as possible.*
2. *Give preference to carers when employing people part time. This would help the part time carers. Give full time carers more time off (more respite) & enable them to have preference in learning/participation in small group situation to learn skills to help them keep up with technology/or job preference. Small local groups would be good. Decentralise.*
3. *Don't send them off to agencies with no support most agencies are after the cash and no help in return some love ones just don't understand and agencies have no idea of their disability.*
4. *Make Housing Available and Affordable. Make it possible for them to acquire courses for skills or to acquire work if they are so inclined and capable. Provide support workers, case management with ongoing support- not for a few weeks. To help them keep on track and check they are not being disadvantaged.*
5. *Raise the disability pension. Raise the cut off point for people to qualify for the carers pension (we miss out by about \$500 pa).*
6. *Give them more money to live off and give the carers even more than disability support pension dose not replace our full time jobs but we work 24-7 caring for our charge. Or let us earn more money without losing the pension.*
7. *More grants and funding. Help with purchasing power wheelchairs. My wife has had NO financial help from the Government to help with getting a modified car and three Power-chairs over the past 10 years. Fortunately we saved hard as we knew my wife had a genetic neuromuscular disease and we would need more and more equipment as she got older.*
8. *Pay the \$\$ directly to us instead of going through organisations who pay staff to misuse the funding.*
9. *More money and assistance*
10. *Instead of just cutting DSP, invent Newstart. Plus with a disability living allowance. Introduce targets for pwd at workplaces and mandatory disability action and inclusion plans in public sector like in WA including option 7.*

11. *I don't know how you can improve financial security when they are basically on the poverty line through no fault of their own (want to work but can't get employed).*
12. *Allow family to have an official (legal) role in their care, without having to go to the guardianship tribunal. Don't like being classed as an "informal carer" without being able to make the arrangement legal.*
13. *Paid employment opportunities are very scarce. Incentives for employers to employ people with disabilities would help.*
14. *Give us a way we can own our own homes, so we do have financial security*
15. *Stop cutting off Centrelink payments for missing appt., often we are busy not lazy!*
16. *People with disability need to be able to access more funding to enable them to earn enough money so they can have a good standard of living, and not live in poverty like many of them do.*
17. *Making the services easily accessible.*
18. *Free public transport would help some. More affordable housing options. Supported housing options for the differing levels of support needed. Recreational and social activities included in care plans.*
19. *The DSP must be increased. As mentioned above, if my family didn't supplement my mother's income out of our own pockets she could not afford to live. There also need to be greater discounts for people on a DSP for essentials such as energy, water, medications, etc. These things are completely unaffordable.*
20. *Allow them to have enough money to have a quality of life and not just a life.*
21. *I don't have an answer to this - apart from increasing the disability and carers pensions - but that is an unlikely solution to a long term issue.*
22. *Reduce rates of rental, reduce fares on transport, reduce their gas/electricity or give them gst free, raise their pensions.*
23. *Lead by example. Employ someone with a disability in all government jobs e.g., politicians offices? 3 or 4 hours a day, for a couple of days a week, would make an enormous difference in not only*

*that person's life, but the life of the family and carers. Watch ALL organisations very carefully, in administering any moneys given to support someone with a disability. Involve the families and carers much more. The odds of who can be trusted with this money, so that maximum amount will be used to support the person, are certainly going to be the main carer, not a large service provider. Do as the minister says, and give the power back to the person with a disability.*

24. *Understanding the difficulties involved. Not making ignorant assumptions about people's situations- such as about getting a job, being employed, housing costs etc.*
25. *Provide better and more affordable housing options. Provide more support for employment because it is so important for self-esteem and community inclusion.*
26. *MAKE CENTRES FREE OR CANT DOWN FEE CHARGES ALSO SOME CENTRES EMPLOY UNSUITABLE PEOPLE SOME CAN'T SPEAK ENGLISH SOME EVEN IN EMPLOY PEOPLE WHO HAVE TO DO COMMUNITY WORK NOT GOOD THESE PEOPLE ARE PARENTS DID NOT ASK TO HAVE DISABLED CHILDREN WE JUST HAD THEM SORRY BUT THAT'S WHAT WE GOT I WAS ONCE TOLD COULD NOT GO TO A CLUB MEETING BECAUSE I HAD A DAUGHTER WITH AUTISM.*
27. *Provide subsidies with utility costs. Continue the HESS program as ongoing support to carers and people with disability.*
28. *Start looking at the needs of the individual and don't group them all in a box then apply funding.*
29. *Incentives to employers.*
30. *If long term DSP- Totally Permanently Impaired (TPI) recipients were given a regular additional payment with the DSP it may relieve pressure on the public housing system -empower the clients, and relieve pressure on the welfare organisations. Service Pension needs to increase FULLSTOP. It astounds me that the Government seem to be trying to 'normalise' the role that military have. There is nothing normal about what these people do. They should be suitably remunerated whilst serving & also suitably remunerated if they require a pension from DVA. It is not acceptable that this is all they get, when they have served THEIR COUNTRY/sacrificed for this Country & then one day they are no longer able to contribute to Superannuation, or have enough money for the basics. It's not ok.They are cast out as collateral damage with not enough money to survive. Therefore for the same reasoning, rates desperately need to be increased. In addition, DVA Clients are not the same as clients whose main income support is from Centrelink. Veterans have very specific & very different needs & the two should remain separate forever.*

31. *By making the funding available to those in need, as well as affordable housing. If they have affordable housing and funding for carers, the disabled can go and become a part of their community and have jobs while having their carer with them. And by doing this the family of the disabled can go and work and this would reduce in family break downs and isolation of the disabled.*

## Section 5: Questions about health services for people with disability

### Summary

<i>Working well</i>	<i>Not working well</i>	<i>Suggestions for improvements</i>
<ul style="list-style-type: none"> <li>• Online health services (e.g. tele-health) and electronic health records.</li> <li>• Choices available through private health insurance, for those that can afford it.</li> </ul>	<ul style="list-style-type: none"> <li>• Cost and time associated with travel in areas outside of major cities for people to see specialists.</li> <li>• Waiting times in the public health system for people with disability.</li> <li>• Inadequate response/management of the health system to certain types of disability (e.g. mental health conditions, Autistic Spectrum Disorders).</li> <li>• Lack of bulk billing offered to people with disability.</li> <li>• Lack of appropriate dental services for people with disability.</li> <li>• Early intervention services where eligibility criteria is based on age of the person - problematic when diagnosis occurs at a later stage.</li> <li>• Costs associated with accessing allied health services.</li> <li>• Accessibility of the physical environment at some hospitals, community health facilities and general practices.</li> </ul>	<ul style="list-style-type: none"> <li>• Greater use of volunteers in the health sector (e.g. for transport to appointments and acting as an advocate for people with a disability).</li> <li>• Home visiting service providers such as doctors.</li> <li>• A 'Trip Advisor' style platform for people with disability to provide feedback on their health care experiences.</li> <li>• Priority on waiting lists given to people with disability.</li> </ul>

5.5 Difficulties carers have noticed people with disability have in accessing and using health services.

1. *If they don't have private health insurance, they get the run around.*
2. *Times of transition are difficult. We have often fallen into the 'grey area'.*
3. *Understandably but still frustrating is the constant need to travel to Perth for some specialist services. It is more the lack of understanding of Perth receptionists for specialists about the difficulty of travel time.*
4. *Needs are not met for people with disabilities sadly the system seems to be overstretched, understaffed and unsupported itself. There are massive waiting times on every level especially at local hospitals. This is not a reflection of the nurses or ambulance people themselves. It is not supported financially. The government do not provide enough funding for services. If there was more available we may see some more preventative incidents happening, including outbursts, psychotic episodes, less frustration and aggression, less suicide rate. Proper management is needed for all with disabilities. It comes back to support and case management. Proper ongoing care and monitoring and for this these services need to be better supported.*
5. *It just takes too long to access services, waiting years for things is ridiculous and unless you have someone in your family that is able to push and nag and ring every body a million times you could just rot. It's tragic, just about every disabled person "falls through the cracks" in the system.*
6. *We have found it impossible to get mental health care for our daughter with autism nor could we get rehabilitation for her after a major stroke.*
7. *Cost - the aged pensioners are bulked billed but not all doctors bulk bill disabled pensioners.*
8. *Tried several dentists before one had suitable accessibility and suitable accessible dental chair.*
9. *Lack of advice re funding. In the Autism/ASD community, just today we were talking about the lack of information regarding what is available. My daughter missed out because not diagnosed until she was 13. Then just today I found out that there was another service she could have used up til her 15th birthday. She's now 16. Is there an option to choose our own treatment/services?? What about for our children, if we make a decision which health services don't agree with??*
10. *Nothing is accessible*

11. *Went to "headspace". Got a nurse, who admitted to thinking in her native tongue, so was slow in formulating reply. Spent 40 - 45 mins asking me "what I thought my daughter was thinking". Then 5 - 10 mins max with my daughter, talking about nothing relevant to her "sadness". If I access emergency respite I will have to provide her own food, because of her need for Gluten and Soy free food. As if I can plan that ahead????*
12. *Families with disability if they have access to funding in using services like speech, OT, Psychologist then usually we pay double or more. That funding gets swallowed up by greedy organisations, cos they believe it's free for parents. We also have less of selection we can choose to use some of the funding, making us lose the power in the right to choose*
13. *We have found that unless you are prepared and/or able to pay for your own private health practitioners you would be in such long waiting lists that early intervention would be far gone by the time you got to the top of the list. We as a family have had to privately pay for all of our own health interventions and practitioners for the last 7 years which as you can imagine has been quite a financial burden on our family.*
14. *Lack of connectivity and holistic and ongoing coordinated approach to the individual's wellbeing. The red tape and waiting list. We have recently tried to access an Occupational Therapist through our local community health centre (only recently learning of the service and its benefits) after many years of struggling and my husband's health significantly deteriorating to be told we had to wait 3 months. Have ended up paying through a private agency with a 2-week lead-time. My husband has been trying for months to contact DHS without any success. It took the private agency one phone call and she has someone phoning us to help us work through what help is available after years of not accessing anything.*
15. *In mental health, access to treatment is often delayed until a person has fully relapsed. Early intervention, although can work well, does not happen for many. Because of the nature of mental illness a person with deteriorating symptoms may not be agreeable to seeking help leaving carers frustrated and anxious, watching the process of deterioration and damage to relationships and recovery.*
16. *My mother has a psychosocial disability. Over the years we have struggled to receive basic support for her. We have always had to seek (and beg) for help. It has never been targeted to her. There is no such thing as proactive healthcare, it's always too little too late. I have lost count of the number of times I have sat with her in the emergency department seeking help, waited for hours and hours, only to be seen for under five minutes and sent home with no help. When she has been hospitalised she has been discharged with absolutely no follow up. When she has been*

*able to identify to services that she is becoming unwell before she hits rock bottom they have ignored her - there's no such thing as prevention in public mental health.*

17. *The financial cost or funding availability has a major impact in accessing health providers. The therapies cost is expensive.*
18. *My son had an operation at the Royal Children's Hospital a year ago. I told them about his autism and likelihood of absconding when under stress. But because he was "OK" at the pre-op meeting, they didn't plan for him absconding ... so then were very surprised when he tried to escape the pre-op theatre and needed 8 adults to contain him. Later they said that next time they would need to sedate him differently. I said "but I told you about this today - why didn't you sedate him differently today?" Health services need to listen to the experience of parents and not ignore them when they say "this is likely to happen."*
19. *We have had an unpleasant experience with professionals in the health sector "writing off" a person too soon, and inappropriately suggesting that rather than further treatment and rehabilitation, the (young) person instead be shunted into an aged care facility for the rest of their life. Thankfully, through my advocacy and the person's determination and stubbornness - this did not occur. But it shouldn't have happened in the first place, and it shouldn't have happened to us at a time when we were the most vulnerable and stressed.*
20. *Most of the needed services are either based in big cities or large regional towns. Many people in Perth for example have long distances to travel to access the need services. An example of this would be the fact that I have to drive for at least 1 hour each way (if the traffic is nice) to get my daughter who has an acquired brain injury to see her neurologist. I am one of the lucky ones, others have to drive 2 or 3 times further than me.*
21. *Wheelchair accessible what a joke I have trouble getting up some ramps and the doors are worse. I helped a gentleman recently get to the Dr in Mt Barker SA as he was going up the ramp his VERY expensive electric wheelchair almost tipped over backwards.*
22. *Reporting medical information is very difficult for most people with an intellectual disability. Mainstream medical people do not have the time or skill to properly diagnose or treat people with an intellectual disability, especially around the area of mental health. Medicating people is the easy way out. I had to travel over an hour and a half to get to my sons (twins) to their appointments due to there being no paediatrician in the hills.*

23. *Some health services are good, some dreadful. It's the luck of getting good, understanding individual practitioner/s. Many have no idea. Red tape is debilitating*
24. *People in rural areas who need to access specialist medical and allied health services in the city are hugely disadvantaged by cost and time.*
25. *I regularly have take my daughter (who has the disability) to the mater children's (public) hospital in Brisbane, I know this facility is undergoing a major renovation but it's provisional measures for wheelchair access from the car park to the hospital are non existent. I raised this issue with the hospital management and was assured I would be better catered for if I parked in a smaller car park on the hospital grounds, access was through the security gate. There was one wheelchair car park space available, luckily it was not in use, I parked, then I walked pushing my daughter in her wheel chair back up a rather steep hill to find the security guards office (not the security hut I had just passed through) to get a ticket to allow me to park in the space for an allotted time. Then I had to walk back, with my daughter in her wheelchair, put the ticket on display in my front screen, then go about my business of the appt. at the hospital. I might also add I was 7 months pregnant at the time also (Dec 13) ... needless to say I did not choose this preferential treatment for subsequent visits.*
26. *MOST DOCTORS ARE GOOD, DENTIST THEY ARE SCARED OF THEM MY DAUGHTER WAS PUT IN WITH A GROUP OF OLD WOMEN WHILE SHE WAS IN HOSPITAL BECAUSE THEY HAD NO WHERE TO PUT HER.*
27. *Long wait lists for public health services.*
28. *Bulk billing practices are hard to find. Mental health services public are long waiting lists and cyclical private are cost prohibitive with long waiting lists.*
29. *Need support from carer.*
30. *Some of the services my son requires has only been available if I fund the treatment myself, and as much as I would love to see my son improve, due to not working because of my caring role my sons condition continues to deteriorate which puts more strain on the health care services as he requires more hospital visits as well as being monitored closer by his specialists.*

5.6 What carers think Government, organisations or other groups could do to improve access and use of health services by people with disability.

1. *Would be great to have government funded community organisations that could rein in volunteer helpers and organise help for those who need it e.g. transport to medical appointments/act as advocate for disabled person who does not have a carer.*
2. *Self-directed services will help to alleviate the issues above. However, people will still need access to consultative services to know what there is available and to make the best choices - particularly those just beginning the journey.*
3. *Technology is making HUGE improvements with online access to specialist information without the need to travel for non-emergency situations. I hope the government will continue to fund links to specialist practices and faster internet access for isolated, remote and satellite quiet rural areas.*
4. *Home-visiting service providers.*
5. *As above, answered in previous question.*
6. *Liaise with hospitals better, people need to be identified at the moment they become disabled and then followed and supported from there.*
7. *More poster style info on computer, Facebook etc. More EXPOs where both the carer and the person being cared for can attend. We went to one recently in Butler and gained so much information that we didn't know before. All pamphlets were bright and colourful and easy to read as well as containing a web site and a contact email address. Make rooms used by all dentists, podiatrists, physios etc. easily accessible.*
8. *Honesty to start with. Share the information. Don't take an "Us & Them" attitude. Other people are NOT better than those of us with disabilities.*
9. *Cut waiting times.*
10. *Fix it. It's not rocket science. Get disabled people to feedback on their health care experience and provide a trip advisor style platform for feedback about service and access.*

11. *Reduce waiting lists. Listen to parents gut instincts. Provide funding for those who are in the grey area.*
12. *Organisations, medical professionals, therapists be monitored on their prices and those ripping off the families be excluded.*
13. *I think the NDIS idea is a good one - as long as it can be made financially viable for the country. Some parts of the NDIS funding are so small that service providers in our area are closing their books as they are making such losses under the scheme and then other service providers are making huge profits.*
14. *Reduce red tape and seeking to develop a holistic and connected approach from time of diagnosis.*
15. *Ongoing support for people with a long-term mental illness to enhance the ability to intervene as early as possible in an impending relapse. More psychological support to help people with a mental illness understand their illness and better manage their symptoms.*
16. *Public mental health services need to broaden to include prevention, not just acute care when it's too late. They need to be more assertive/proactive - they wait for clients to come to them, not the other way around. They also are only short term, but we need something that is long term - this illness is not going away. Also private providers are completely unaffordable for people on a pension so we are stuck with a completely inadequate public system.*
17. *I had to borrow money, which I (carer) am still paying back for my son to go to a dentist over a year ago.*
18. *By making these services available and accessible more with lower cost.*
19. *Include behavioural questions in medical assessments then make plans for when those behaviours emerge.*
20. *By providing adequate care, and being patient focused, not simply focused on the \$\$\$ and budget and costs.*
21. *Allow more places and times to be allocated to smaller hospitals such as Swan Districts or Kelmscott so that rural people cant get to their appointments without causing undue stress with the added travel.*

22. *Bring back Drs who do home visits reduce fees make them more accessible.*
23. *Make it affordable and accessible for people with a disability to access counsellors and psychologists, and naturopaths. These people are trained to listen to the whole person and their situation.*
24. *Simplify the system. Fund it better.*
25. *Provide more local services or subsidise travel and support costs.*
26. *LEARN TO UNDERSTAND THEIR NEEDS MOST DOCTORS ARE GOOD SO ARE NURSES DENTAL DONT HAVE A CLUE.*
27. *Give priority on waiting lists to people with disability.*
28. *Implement further health services.*
29. *And if this happens not only does it put more financial strain on the government, and will continue to worsen for the disabled until centres are being made more accessible to decrease some of the disabled's needs worsening. In some circumstances deterioration is unpreventable, but there is also a large number whose conditions remain stable with the right rehabilitation being offered at a long term basis, by doing this most cases people stay out of hospital longer and play an important role in their community.*

**Section 6: Questions about personal support services and community services for people with disability**

**Summary**

<i>Working well</i>	<i>Not working well</i>	<i>Suggestions for improvements</i>
<ul style="list-style-type: none"> <li>• Positive experiences with community services for the person with disability, families and carers.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of advertising of services.</li> <li>• Waiting lists for respite services.</li> <li>• Disability services excluding families/carers (e.g. not incorporating their viewpoints, not providing support).</li> <li>• Community services not adequately responding to situations where a family has multiple members with a disability.</li> <li>• Community services under-resourced/under-staffed and staff being overworked.</li> <li>• Lack of stability/short-term nature of services.</li> </ul>	<ul style="list-style-type: none"> <li>• Greater availability and affordability of respite services.</li> <li>• A single database of community services.</li> <li>• Targeted advertising of services.</li> <li>• Consumer control of funding/choice in what services they choose to use.</li> <li>• Higher standards for personal support workers/people working in the community sector.</li> </ul>

6.4 Difficulties carers have noticed people with disability have in accessing and using personal support services and community services.

1. *My son is 27 years old and I have never had a night away from him, he has been on the waiting list for weekend respite for over 2 years and then if he gets it, I have no choice in where he can go. I want to be able to know that he is in a place I have been able to choose with people I am comfortable with. A weekend respite with his friends and in a place I approve of is essential. You cannot just put him in a strange house with strange people, this is very difficult for people with Autism.*
2. *What community services?? It's all about the disabled, not the family or the carer.*
3. *There is no support to help.*
4. *In Albany it is always about staffing of support services. There are never enough employees and they are overworked.*
5. *There is difficulty in accessing services for support, there is difficulty getting adequate support, there is difficulty getting ongoing support for the long term. Things change things don't work and then people drop off and then we have the challenge of accessing new service elsewhere and at some point. There is nothing left to access I imagine. There is no stability for these people. We must be able to have faith in our services and supports so that faith and trust develop and people with disabilities can grow more confident in achieving.*
6. *The people doing the liaison work with disabled people are caring and try hard but they are under resourced and only have access to services provided by their own group i.e. my daughter has a person that comes to help with getting her back in to the community but doesn't work with the person from the guide dogs that is doing the same thing! Unless we, the family coordinate things it dissolves into chaos.*
7. *Cost again, we have to pay for the personal support workers but to that we end up with no money, they wont touch the wheel chair so they wont take them shopping they don't dust, they don't do much at all the one we have in our community (Melton Vic).*
8. *Finding the contact info for the service.*
9. *No choice and control.*

10. *No funding = won't talk to you.*
11. *Families can't afford these services, being on a carer's benefit and the Respite is always unavailable, families are usually under so much pressure and end up burning out.*
12. *We have had nothing to do with these services due to long waiting lists and us having to go down the private sector path.*
13. *Refer previous comments.*
14. *Transport can be an issue. Either illness symptoms or cost. Options available. In mental health community services if a person is unable to attend programs they have been excluded.*
15. *There are services like this suitable for my mother.*
16. *We don't qualify.*
17. *We had a caseworker once, and she had certain ideas, and wouldn't take into account our wishes.*
18. *Most support services only take into account 1 person at a time. What about those with more than 1 person who is being cared for??*
19. *I am also a carer and have a client who once a week would like to go bowling not too much to ask I would have thought but the dramas involved have now put him in depression.*
20. *The answer to this question is not clear. It is going to be very different for every person. Having worked in this area for a long time, I've heard lots of very unsupportive stories, but also many positive ones. Mostly, if the situation is very complex, and lets face it there are a lot that are, these people are deemed too hard and are often exited from services. This puts great strain on the family.*
21. *Not enough notice is taken about the effect on families. Siblings are not well enough supported and neither are parents. People's real needs are not understood or taken into account - they need to fit in with what is the current idea about what should happen and how things should be.*
22. *It comes down to cost. There is never enough money to support people with severe disabilities to have the same quality of life and opportunities as others have.*

23. *Have you ever had to use a disabled public toilet???*
  
24. *YOU'RE JOKING HERE IN QUEENSLAND THERES NONE BUT ITS UP TO BLUE CARE ARE UNITED CHURCH TO HELP THEY DONT HAVE ENOUGH STAFF TO HELP EVERYONE AFTER A YEAR THEY FORGET YOU.*
  
25. *Lack of funding/availability of services.*
  
26. *Lack of knowledge of availability.*
  
27. *Funding to get these services into place is extremely hard and long waiting lists, or is often too expensive.*

6.5 What carers think Government, organisations or other groups can do to improve access and use of personal support services and community services by people with disability.

1. *Access to good safe respite and reliable safe support workers is essential and the cost of this is also prohibitive for most carers. AGAIN more money is needed to supply more respite houses etc.*
2. *To train agency staff how to handle clients with head injury and more support not just looking at how much money the agency is getting for not supporting clients.*
3. *Put more funding into organisations like Silver Chain. Keeping people with disabilities in their homes is a LOT cheaper in the long run than housing/hospitalising them.*
4. *By providing access - there is too many hoops to jump. Families and carers are forever trying to access services to get support. It is when the carers and families fall apart. The whole system needs to be supportive so that the carers and workers and families are able to cope. By providing accessible, affordable and ongoing supportive care for people with disabilities and providing enough of the same of community services.*
5. *One database.*
6. *Make all councils employ people not just use volunteers.*
7. *More advertising in appropriate places and more education for the wider community so they become aware how they can help a person with a disability. My wife's chair got bogged in some mud and people around didn't know whether to approach us or not. I had to ask the to help.*
8. *Give the \$\$ directly to the families and let them decide which services they wish to choose. Less \$\$ wasted paying some organisation to 'monitor' it when they waste so much time/money themselves - their wages for a start are astronomical.*
9. *Listen to what I'm saying. Don't ring "lifeline" when I burst into tears in frustration at not being listened to when I am asking for help. Don't tell me "but she's in a safe and loving home". I won't be around forever. I want her to become semi independent now. Not put into "crisis" accommodation that is not suitable for her when something happens to me.*
10. *More support affordable respite and free respite would help hugely. Provide transport assistance for people with a mental illness who are isolated and not able to use public transport.*

11. *My son's life is evolved around home - we can't afford to go out. Unless you include grocery shopping?*
12. *By providing choice. A real choice. By giving patients and their families a say.*
13. *Incorporate multi family listing into your services. Provide more support not just for those with siblings with a disability but also for siblings who also have a disability and maybe take into consideration that not everyone has an extended network of family and friends who can help or give the family and the person with a disability a break.*
14. *Get off their butts and go live as a person with a disability for a month at least then see what gets done.*
15. *Listen to the families!!!!!!!!!!!!!!!!!!!!!!*
16. *Understand the difficulties that may occur from logistical difficulties- such as getting there if services are a distance from home, to recognising individual needs not just fitting into what is believed by govt. etc. to be the right thing. Employ more people. Totally overhaul how support services run and how workers are educated.*
17. *Provide support workers at community social and recreational activities so people with disabilities can attend.*
18. *DO MORE WEED OUT THOSE THAT HAVE BACK PAIN OR CAN WORK I THINK ALL PEOPLE WITH A REAL DISABILITY AUTISM BRAIN DAMAGE IN WHEEL CHAIRS SHOULD BE TREATED BETTER THAN PEOPLE WHO DO DRUGS OR DRINK THEY DID IT THEMSELVES PEOPLE BORN OR OLDER PEOPLE WITH DISABILTY SHOULD COME FIRST THEY DONT THEY ALL GET TREATED THE SAME SOME PEOPLE LIKE MY DAUGHTER ARE JUST CHILDREN IN MIND THEY NEED PROTECTING.*
19. *Provide further support services.*
20. *Look at the entire family unit/ look at family as a whole. Instead of just dealing with client. Provide services where the needs of client are met, without dismissing the family unit. Whether it's because "sorry our funding doesn't allow us to provide that" or "sorry our service only provides for the client - you'll have to make arrangements for the children" "sorry we haven't heard of that before, don't think we can do that". Its the PEOPLE that seem to be the barriers to accessing quality service. Nobody seems to be capable of dealing with the variables that should be EXPECTED within the disability sector! Set higher standards for people working within the sector!!*

*Don't lower the standards just because there is a crisis, and it is known that there will be tens of thousands position shortfall in the near future. Make it a position held in high regard, a position to strive for, to demand quality outcomes. Better for service providers and clients! (Same problem with teaching I would like to add right now).*

21. *Disabled need to be looked at and treated with respect and fairness, currently they are just left to wait, that is not respected, that is making them feel worse than they and there families already feel.*

## Section 7: Questions about rights and justice for people with disability

### Summary

<i>Working well</i>	<i>Not working well</i>	<i>Suggestions for improvements</i>
<ul style="list-style-type: none"> <li>• Potentially higher rate of community consultation with people with disability.</li> <li>• ‘Don’t Dis My Ability’ type programs.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of information about services to assist with the rights and justice of people with disability.</li> <li>• Confusion regarding processes for raising complaints/legal processes.</li> <li>• Lack of legal control and protection of carers.</li> <li>• Pressure placed upon the carer to act as an advocate for the person with a disability.</li> <li>• People with disability not having the confidence or feeling “too scared” to raise complaints, particularly those with a mental health condition.</li> </ul>	<ul style="list-style-type: none"> <li>• Greater availability of formal disability advocates and advocacy services for both people with disability and carers.</li> <li>• Funding self-advocacy groups for people with disability (derived from section 2).</li> <li>• Ensuring advocacy services are included as part of the National Disability Insurance Scheme.</li> <li>• Actively incorporating people with disability in organisations instead of just using unpaid volunteers.</li> <li>• Reducing barriers for people with disability to testify.</li> </ul>

7.2 Difficulties carers have noticed people with disability have with their rights and access to justice.

1. *People with disability are most likely unable to express their concerns or make suggestions to improve their rights and access to justice. The carer has to try to ascertain what is needed and be an advocate. It is very difficult. I guess it depends on what the disability is. Advanced Parkinson's Disease means difficulty with speech, swallowing, eating, bathing, moving, balance, tiredness, lack of motivation, difficulty moving in bed ... and on and on and on. We had a court case against us and it took four hours for the solicitor to get info from my husband, which would normally take half an hour. We had to pay based on time taken ...*
2. *What rights do they have?*
3. *Don't know where they can get help with this ... there is not enough information about it.*
4. *People seem to get impatient with people who have difficulty vocalising their concerns.*
5. *From what I can work out, under the current government people are too scared to make a noise in case we lose more \$\$ or the minuscule support we currently have. There is not enough support for the number of PWDs out there - think of the ratio of PWDs to 'normal' people. Most normal people only look at the \$\$ which goes into their pockets.*
6. *In WA you can be locked up for years without charge.*
7. *Depending on the disability.*
8. *I'm not able to have any legal control over her care, can only act as an informal carer. Told Guardianship is only as a last resort, and usually not given to family. Daughter not able to make will or power of attorney unless I supply a "certificate of competency". She IS on the Autism spectrum with a severe language disorder.*
9. *People with intellectual disability need advocates to assist them with expressing their views, taking action to enforce their rights and obtaining access to justice.*
10. *No one listens to our rights for inclusive education, training, support. Carer's aren't supported and DSQ is a joke.*
11. *We have not had anything to do with this as yet as our child is still quite young.*

12. *Policies seem to somehow make this difficult and require a significant amount of energy and confidence.*
13. *Lack of confidence or awareness of processes inhibits many people with mental illness from exercising their rights.*
14. *The mental health legal centre no longer has funding, and that was the only place in the state that specialised in legal services for people with a mental illness. There are no mental health advocacy services available that I am aware of. We are too scared to make a complaint to a service in case they take this out on us.*
15. *The person I care for has severe expressive aphasia, which means he has great difficulty in communicating. He is still extremely intelligent and can make his own decisions, but he can't talk with words, he can't on the 'phone, he can't write a letter, he can't write an email - which is how most people communicate - so he is very disadvantaged.*
16. *Depends on their ability to communicate but have been fighting for over six months with no luck or feedback.*
17. *This is the most vulnerable group in society. It is very easy to dismiss their concerns.*
18. *Not understanding the process. Not having enough support in going through the process. It all gets too much - you get sick of fighting for every last morsel of understanding or help.*
19. *Particularly in the school system it is difficult to get what you need.*
20. *THEY HAVE RIGHTS AND CAN USE THEM BUT A LOT DONT UNDERSTAND HOW TO USE THEM OR MENTALLY UNABLE TO.*
21. *I think there is a higher rate of consultation with people with disabilities. I think this has resulted in people having a greater sense of their worth, awareness of the power of their own voice and ways in which they can make a difference in controlling their own lives. The focus on the NDIS is changing the way people think. It is a great thing.*

7.3 What carers think Government, organisations or other groups could do to improve the rights and access to justice by people with disability.

1. *Strong advocacy for the disabled. Special dispensations. Legal assistance for both disabled and carer.*
2. *Listen to what they are saying.*
3. *Education! More contact with people with different types of disabilities and showing them respect.*
4. *Be honest. Stop lining their pockets and put the \$\$ where it is supposed to go. Actively incorporate PWDs in these organisations instead of having others (who really can't comprehend what we go through) and PAY the PWDs instead of using them as unpaid volunteers. No one likes being used or taken advantage of just because they can't do something/have a Disability.*
5. *Change the rules and allow pwd to testify.*
6. *Have some compassion.*
7. *Disability advocacy organisations need to be funded and included in the rolling out of the NDIS.*
8. *Help every family with a disability to plan for the future from start to finish.*
9. *An advocacy program available to all people with a mental illness. An advocacy program carers can access in regards to the rights of their caree.*
10. *My son can't talk, read or write. And I can't get anywhere on his behalf.*
11. *Provides a special forum or organisation where people could express and give their feedback.*
12. *By making it easier for people with aphasia to deal with them. Contact the Australian Aphasia Association for further information about this serious condition.*
13. *See how they manage living in a wheelchair or going deaf or blind and not just for a day or night.*
14. *Listen to carers and families!!!!*

15. *Recognise that it may be exceedingly difficult for them to access justice - time, distance, communication difficulties, energy to do what's needed, too much to cope with already etc.*
16. *TEACH THEM SHOW THEM.*
17. *More investment in Advocacy services.*
18. *The gaps I see in the NDIS are mainly in terms of advocacy for people with disabilities. With so many more accessing supports by the full rollout of the scheme I would think that more people might require advocacy and legal support. More funding needs to be injected into this area so that it supports disability reform and views it with a more holistic approach.*
19. *Awareness in schools. "Don't dis my Ability!" With Education about young carers also! It all starts with campaigns by advocates within the school system. School resource packs are essential. Direct funding for these types of things is necessary. I would hope then that the current Advocacy groups that assist to improve the rights and access to justice for people with a disability would be sufficient.*
20. *Put strategies in place for them and be there to support them through the process from start to finish, not just saying that there are things in place and nobody doing anything.*

## Section 8: Questions about the National Disability Strategy

### Summary

<i>Working well</i>	<i>Not working well</i>	<i>Suggestions for improvements</i>
<ul style="list-style-type: none"> <li>• The positive intention of the strategy.</li> <li>• The National Disability Awards and promotion of the strategy through this avenue.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of awareness of the strategy amongst carers.</li> <li>• Lack of information about what has come out of the strategy in a practical sense.</li> </ul>	<ul style="list-style-type: none"> <li>• Greater concern with the human rights of people with disability.</li> <li>• More comprehensive roll-out of the National Disability Insurance Scheme across Australia.</li> <li>• Targeted promotion of the strategy using local newspapers and the television rather than the internet.</li> <li>• Incorporating more personal stories of everyday live of people with disability, their families and carers.</li> <li>• Education for people working in the disability sector (e.g. CEOs) on how to talk to, and about, people with disabilities.</li> <li>• Greater action (in a practical sense) to enact the strategy.</li> <li>• Revising the strategy as time goes by and ensuring community members continue to be involved in the implementation of the strategy.</li> <li>• Greater support of the strategy from politicians.</li> </ul>

8.2 The areas of the National Disability Strategy carers think seem to be working well or not so well.

1. *No. Sorry.*
2. *Nothing's working because it won't be in Queensland until another 2 years*
3. *Unsure.*
4. *No areas work well for us.*
5. *I organised and got 406 signatures for the Coffs Harbour April 2012 NDIS Rally. 2 years later and what is being done??*
6. *Difficult to see given the terribleness of the First Report. How would we know?*
7. *I am aware of it but that's all. I have no understanding of how it will help us only that the Liberals do not want to support it.*
8. *The NDIS is happening, albeit slowly in Qld - this is good. I am concerned that human rights of people with disabilities are not being taken seriously. The NDIS needs to recognise the need for advocacy for people with disabilities and ensure that disability advocacy programs are funded and properly set up as part of the NDIS.*
9. *If no new money, how will all those who as missing out benefit? Queensland not participating at this stage. Either parents/carers will have to set themselves up as mini employers OR administrators charge a fortune to do payrolls, insurance, workers comp, regular reporting, hiring staff etc. Leaving little funding for care.*
10. *There doesn't seem to be much more money coming through for additional carer support staff, respite, etc. despite more carer recognition.*
11. *Really don't know enough about it to make comment here.*
12. *I've heard of it, but have NO idea what it means? Especially for my son and myself?*

13. *Having worked in disability area for many years, I'm sorry to say I haven't noticed any ground breaking differences in other people's lives in general. In my family, no real differences either.*
14. *Have had no indication of anything to do with it so possibly it is having more of an affect on organisations than the people who need the changes.*
15. *NO JUST BEEN TOLD.*
16. *The National Disability Awards helped me gain awareness of the strategy. It offers some wonderful direction. Very positive.*

8.4 What carers think Government, organisations or other groups could do to be able to influence more open attitudes in the community towards people with disability.

1. *Train the kids and have hands on support for them.*
2. *More education in schools to encourage more empathy, incentives for employers to "give them a go".*
3. *Advertising raises awareness, ads that make people think of disabled people as a normal part of the community, we don't need ads to tell us the bloody NDS is on its way, what a waste of money that was! More incentives for employers to hire disabled people, easier access to public spaces for the disabled, the more of us out there in the community the more used to us people will become.*
4. *Put more info in local papers and on the TV as most disabled people and workers don't have internet as its too expensive.*
5. *Unless people know someone with a disability, they just turn off and think it doesn't apply to them.*
6. *It is true in some areas of community some people are more aware and considerate. However, there are a LOT who don't care. Facebook is an excellent place to research community attitudes towards PWDs/people at a disadvantage. It's disheartening and cruel.*
7. *Empower people with disability to do this themselves.*
8. *I believe the general public think thus is going to cost them (more tax) and people who don't have to deal with it honestly do not care.*
9. *More support, more information, and don't take away what you promise the year before*
10. *Education and acceptance.*
11. *Reduce red tape and barriers between government agencies.*
12. *Let us all be equals - and a bit of compassion would go a long way. I don't even bother anymore - I'm sick of being shutdown.*
13. *Have people with disability working for them - remove stigma!*

14. *By showing that people with disabilities are people - real people - with hopes and aspirations, just like everyone else in our society.*
15. *Employ more people with a disability.*
16. *Recognise that this is an actual real part of life - not to define people by their abilities or caring role but that this is real life.*
17. *Education has to be a corner stone & more personal stories of everyday life, not just the good days. I think this idea that all people with disabilities are very well able to mix & mingle with general society is misleading & totally misrepresenting all those people that have very complex needs, they have the same right to be included & enjoy life but our facilities & attitudes simply do not allow this!!*
18. *MORE ADS MORE AWAREDESS AS I SAID BECAUSE I WAS CARER I WAS TOLD I WAS UNSUITABLE TO JOIN A GROUP SOME PEOPLE THINK CARERS ARE OVERPAID WHAT PAY FUNNY OR THEY WILL BLAME YOU EVEN BEEN TOLD SHE HAVE GOT RID OF MY DAUGHTER ABORT HER OR STARVE HER TO DEATH AS A BABY I RENT AND HAVE REFUSED A PLACE BECAUSE OF MY DAUGHTER YET SHE SO CLEAN AND LOOKS AFTER THINGS I AM AN EXTRA GOOD TENANT PEOPLE WITH ANY DISABILITY SHOULD BE ABLE TO BUY A UNIT OR PLACE THROUGH THE GOVERNMENT.*
19. *Positive role models and non-derogatory remarks.*
20. *Educating people within the sector on how to talk to and about people with disabilities. I recently read a letter written by a CEO of a disability organisation that used words such as "victim". It also highlighted that people with disabilities were somewhat deserving of our pity and were essentially in need of your charity dollar. If people in the sector can't get it right then what hope have we got of expecting the general public to get on board. I still get asked about my son by strangers "is he retarded?".*
21. *See last comment about school resource pack.*
22. *Help them and their family by making it easier to access the community.*

## 8.5 Additional comments carers made about the National Disability Strategy.

1. *My son needs help he would love to work but no one will take him on and support what he wants. Gets a job and can't keep it. No support no job.*
2. *Why can't people either a disability be able to use it now, instead of when it arrives in this state? It should have been brought all over Australia at the time it came into force.*
3. *Keep it going!!!!!!*
4. *It seems the current government are delaying it to go ahead. Like everything else that has always been the same way... we get the run around. Promises that never happen ... and now we hear words like privatisation. What?? !!*
5. *My comment is don't waste anymore of the precious money on the constant revision of "policy and procedures" to the point where there is no money left to implement any of the recommendations. No politician needs to go overseas to see what another country is doing about this, that's what a telephone and the internet is for. We need action, not another committee!!!!*
6. *Its crap*
7. *Not much is happening in WA.*
8. *I'm truly disappointed that it's been so long and we're still at the starting block. Then again, that's no surprise. Truly disappointing.*
9. *Great strategy. About time it was enacted, don't you think?*
10. *How about some real information to the carers. I have no idea how it is to benefit us and have real concerns about my son's future.*
11. *The strategy needs to be constantly revisited and workshops held annually around Australia to inform and consult with the disability sector about the strategy in order to check how it is being rolled out.*
12. *More Government mumbo jumbo, which will probably change after each election. Just passing the buck between state and federal funding. It quickly falls off the horizon. It is now more than*

*three years since it was signed and I don't believe it is as relevant as it should be for many people affected by disability. The strategy must be intentionally brought back for review regularly.*

13. *NDS will not give families the power to choose services but for services telling families about what they think we should spend it on ...*
14. *I don't know what it is - so can't comment.*
15. *I am unable to comment because I am not aware of how the National Disability Strategy is going to impact or improve the life of me, or the person that I care for. Perhaps this is an indication that somehow, we have slipped between the cracks, and don't have the support, nor information, to help us live a fulfilling life. We live in rural Victoria, and feel very isolated and unsupported when it comes to adjusting to our new life, coping with disabilities.*
16. *Make it more about the people who need it, not the organisations implementing it I am very concerned about the emphasis in 'Young Carers'. Kids need to be kids, not be identified as carers. There needs to be recognition for sure but great care needs to be taken not to force them into too much responsibility and then give them outings to celebrate this. The person needing the care MUST be able to get it from somewhere else and the young person must be protected from losing the opportunity for their own growth and individuation by being overly identified with this role*
17. *NOT IN QUEENSLAND YET THINKING OF MOVING STATE TO WHERE IT IS BUT HOUSING IS MY TROUBLE.*
18. *I think it offers clear direction and it is positive. Great work!*