Ensuring a good life for people with a disability and their families

Supplementary Submission

The voices of carers in response to the Productivity Commission's Draft Report on Disability Care and Support

Carers Australia
June 2011

About Carers Australia

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness, chronic condition or terminal illness or who are frail aged.

Carers Australia believes that all carers should have the same rights, choices and opportunities as other Australians. Carers should be able to enjoy optimal health, social and economic wellbeing and to participate in family, social and community life, employment and education.

Carers Australia's members are the eight state and territory Carers Associations.

Acknowledgement

Carers Australia wishes to thank Carers Victoria, particularly Gill Pierce and Penny Paul for the preparation of this supplementary submission on behalf of Carers Australia. We also wish to acknowledge the work of other state and territory Carers Associations in promoting the work of the Productivity Commission's Inquiry into Disability Care and Support. This has provided a strong base on which to develop this supplementary submission and reflect the voices of carers.

Title:	Response to the Productivity Commission's Draft Report on Disability Care and Support Supplementary Submission: The voices of carers in response to the Productivity Commission's Draft Report on Disability Care and Support.
Date:	June 2011

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INTRODUCTION

Carers Australia and the state and territory Carer Associations have assisted many carers of people with a disability to be involved in all stages of the Productivity Commission's Inquiry into Disability Care and Support. Carers Australia responded to the Commission's Issues Paper in our submission dated August 2010, following consultations with carers in July-August 2010.

An evidence-based submission from Carers Australia entitled 'Ensuring a good life for people with a disability and their families' was provided in response to the Productivity Commission's Draft Report on Disability Care and Support on 16 May 2011. The content and recommendations by Carers Australia in the submission were informed by consultations with carers. This comprehensive summary of carers' views could not be included in the submission to the Productivity Commission; they are instead included in this supplementary submission.

Consultations with carers on their views concerning issues raised in the Productivity Commission's Draft Report were facilitated by funding from the Department of Families, Housing, Community Services and Indigenous Affairs. Carers Victoria also made a commitment at the Disability and Carer Congress (2 & 3 May 2011) to ensure that the views of carers on the Draft Report were sent to the Productivity Commission.

This supplementary submission includes the views of state and territory carer association members and constituents and some service provider organisations, obtained through a range of approaches. This submission provides the results obtained from a small quantitative survey of carers and also summarises the responses to the questions raised in the Commission's Draft Report elicited during a number of group consultations with carers and as part of Carers Australia's two workshop sessions at the National Disability and Carer Congress on 3 May 2011. The supplementary submission includes direct quotes from carers on the questions raised by the Productivity Commission.

In engaging carers with the Draft Report we have:

- engaged directly with 368 carers and 60 providers to ensure our response to the Productivity Commission is representative of the views of carers;
- promoted participation in round 2 of the Productivity Commission's Inquiry to hundreds of carers and providers who are members of state and territory Carer Associations;
- summarised key themes from consultations with carers and providers;
- submitted an evidence based national response to the Inquiry's Draft Report on 16 May 2011; and
- submitted this supplementary submission on the key issues and themes raised by carers and providers.

CONSULTATIONS CONCERNING RESPONSES TO THE DRAFT REPORT

These included:
- two group consultations with a total of 124 carers in inner and outer metropolitan Melbourne (numbers respectively were 20 and 104)
- an electronic second survey of 20 carers who were engaged in national consultation workshops concerning the long term disability care and support scheme in 2010
- 240 registered participants for Carers Australia's sessions on the 'Implications of the NDIS for families and carers' at the National Disability and Carer Congress 2011. These included an estimated 180 carers and 60 providers, and
- participation in a consultation with 44 carers in Gippsland in collaboration with Carers Gippsland and the Disability and Carers Alliance.

Carers Australia is delighted by the numbers of carers who made personal submissions to both stages of the Inquiry. The extent to which this was an outcome of their engagement with national, state and territory Carer Associations is difficult to quantify.

ANALYSIS OF THE VIEWS OF CARERS

Our analysis of the views of carers combines:
- Quantified responses to structured questions from 40 carers using Survey Monkey combined with responses at a small group consultation in inner metropolitan Melbourne. These surveys included the presentation of brief outlines of the draft recommendations of the Productivity Commission in advance and the recording of responses.
- Key themes recorded from carer and provider responses in large group consultation sessions which include Southern Metropolitan Melbourne and the carer workshops at the National Disability and Carer Congress. At the larger consultations, carers and providers were asked to respond (in groups) to a narrower set of questions.

THE QUANTIFIED VIEWS OF 40 CARERS

1 ELIGIBILITY

1.1 Do the proposed eligibility criteria (for the NDIS) seem appropriate?

Responses to this question indicate 80% of surveyed carers broadly supported the eligibility criteria and thought:
- eligibility needs to be clearly established
- the scheme should start narrow, then widen, but some carers were anxious about their care recipient meeting the eligibility criteria, including those with a mild or moderate disability, a psychiatric disability, autism and those with high functioning Asperger's Syndrome.

1.2 Should people with a psychiatric disability who need regular ongoing care and support be eligible for the NDIS?

Inclusion of people with a psychiatric disability was supported by 80% of quantified responses. Some carers argued that this group are just as disabled as a person with a physical or intellectual disability. Others supported their inclusion provided there was ongoing mental health treatment and a care plan in place.

Those in disagreement considered that care and support of people with a psychiatric disability is a separate issue that should be addressed by mental health funding.

1.3 If 'yes' what services should be provided by the NDIS for this group of people?

Carer views included:

- whatever they require
- the training of all paid staff in mental health issues
- in home support if required; some re-education and assistance to re enter work force where applicable
- residential care costs and independent living support when needed, and
- supported employment costs and programs.

1.4 If 'yes' what services should still be provided by the mental health sector?

Carers said:

- ongoing psychiatric and counselling care and employment assistance, and
- 'the mental health system offers too little as it is massively under resourced'.

2 INITIAL PRIORITIES FOR THE NDIS

2.1 Do you think the initial priorities (new cases, very restricted children under 5, people cared for by ageing parents and young people in nursing homes) are right?

65% considered that the initial priorities proposed for the NDIS were right.

2.2 If 'no' what other priorities should be included?

Carers had mixed views:

- 'I think that the family structure supporting the disabled needs to be taken into account as well. Single parent families need to be made high priority as they often have no other supports to fall back on in any way...Single aging parents need to be rated more highly than couples for instance'.
- 'Intellectual Disability should be added to the list above as it is a life long condition requiring life long support to those with an ID and those caring for those with an ID'.
- 'If the NDIS targets new cases and under 5's, families like ours who have been arguing for NDIS for so long will be left feeling totally redundant and uncared about. We have already been waiting for so long!'

- ‘The age group 16 - 25 which is the transition age between school and work. Too many end up on welfare because nothing is done to support employment. Too many carers have to reduce work hours / lose financially at this transition’.
- ‘The building of long term supported accommodation should be top priority because there is a long lead time to getting these facilities set up and many people are in desperate need’.
- ‘People with very difficult behaviour and their families urgently need help’.

3 NEEDS ASSESSMENT

3.1 Should the needs of all caring families be separately assessed?

75% of surveyed carers responded affirmatively. They considered:

- There needs to be a partnership between carers and independent assessors.
- The meaning of ‘reasonable and willing’ unpaid support needs clarification.
- Some people have great support from family; others have little help while some have no help at all.
- Good families are the back bone of any care and it is from the heart.
- Carers have the bulk of the care, the responsibility for decision making in many cases, and many do not have outside unpaid carers to assist. The quality of the care they give can be very much affected by their own personal needs/ ill –health / lack of sleep / lack of rest generally.

3.2 Should care and support focus on both the person with a disability and carers?

Carers thought:

- Everyone is individual – the disabled person and carer go hand in hand.
- ‘Why? Carers sacrifice their own lifestyle to provide the support required’.
- With support to both we have the best working unit you can get.
- ‘When a family has a special needs child, they effectively become a special needs family and this should be the focus of care and support.’
- There should be extra support for those at risk.

3.3 Do carers need additional intervention and support at key lifecycle transitions – after diagnosis, preschool to school, school to work or adult program, moving away from home?

100% of surveyed carers responded in the affirmative. Passionate comment about the need for transition support (for both predictable and unpredictable transitions) included:

- ‘Moving into accommodation needs a transition or trial period – paid care staff must listen and be guided by the carer who often has the specific expertise and understanding of the kinds of intervention and assistance that will most likely work. Too often carers are ignored (as service providers know better) and a crisis situation occurs - then the family are called upon to sort it out’.
- ‘Paying family carers as staff to phase in transitions to care outside the home may lead to improved transfer of expertise, especially in high intensity care situations which involve the need to be aware of how to undertake regular turning, or recognise subtle things like non convulsive status’.

- ‘I will be facing at some stage the transition from home to residential care and I have absolutely no idea how I will handle that change. My son has had only me all his life - he has seen his father go, his grandmother go, carers he became fond of leave, and the older he gets the more he clings to me. In turn I have not had an opportunity in my caring role to make any sort of life for myself apart from him. We will both need support, and reassurance. Many single parents feel they will simply die once their son or daughter goes as they have nothing to go to. Friends have disappeared and many feel they don't fit into 'normal' society having, often, no grandchildren to talk about, and no life savings to take trips with. In turn my son will need huge support from myself in the most positive way I can find. He is totally unaware that residential care awaits him - or that some day I will not be around. He will not easily accept going to a house he has no desire to live in with people he does not know or trust’.
- ‘We are at the key transition of school to post school. I have had to give up my job and I shouldn't have to. This decision impacts on a range of family needs. We need support to fund this transition. We want our daughter to at least aim for some work but quite frankly it would be easier to put her on the pension. We need financial support to fund her employment and TAFE study to improve her ability to hold down a job’.
- ‘Transport assistance, childcare for siblings. Families could benefit from having the support of an advocate or case manager to help the transitions go smoothly’.
- ‘In fact the support should come about 12 months prior to the transition point. I found that I hit a key transition point quite independently of any predictable milestones when my daughter’s weight increased and I could no longer lift her into bed easily or into the car. Her ability to transfer deteriorated. This meant a whole lot of new equipment and I needed to learn new techniques for handling her. Between researching what was available and waiting for the funding to come through, I was overwhelmed, frustrated, suffered a physical injury and ended up in hospital for a week’.

4 INDIVIDUAL SELF DIRECTED FUNDING

4.1 Is individual self directed funding a good way to go?

87.5% of carers supported the NDIS proposal for self directed funding. Qualifications to this view included:

- A mixture of funding types are needed
- The opportunity for self management should be given to all who wish to do so
- There needs to be a realistic amount of money allocated to each package because the community needs to understand it needs to spend money short term to save money long term.
- Respite entitlements should be directed to the carer.

4.2 Will it be a way of shifting power away from providers and governments and towards people with a disability and their carers?

70% of carers believed that self directed funding will shift power towards people with a disability and their families. Qualifications included:

- The need for government to always take responsibility for assisting people with a disability and their families.
- The current limits imposed by the rules of service providers. Self funding will give people with a disability the authority to make their own choices.
- ‘I would hope so....as this will free up money to spend on families not on pen pushers. The only concern here is ensuring that the power and support goes to genuinely

eligible people with a disability and their families (and fairly) - not just to the families that have the communication skills (as opposed to those that don't) or he who shouts loudest (as opposed to those who don't play the system)'.
- Carers will still need support from service providers to plan and manage care services.

4.3 Do you see any risks in self directed funding?

All respondents saw risks in self directed funding. These included a variety of different concerns:

- More responsibility is being placed on carers to set things up (already doing this). Carers are not necessarily in a position to undertake the organising. Carers would need to be experts in finance, legal requirements and organising.
- A system needs to be in place to ensure funding is used as intended.
- There will be people who are unable or unwilling to take on the task, or who lack the knowledge/confidence/ability to make the choices required. There needs to be some sort of 'safety net' for those people who genuinely need assistance with making choices.
- 'It is always open to abuse. I would like to see a qualifying period. eg 3 years of supported funding and then "graduating" to self directed funding (once there is established "good practice" in place)'.
- It has the potential to put too much stress on already stressed carers. People with a cognitive disability may have problems with planning and motivation.
- Claims by paid care workers for injury in the home, wrongful dismissal actions; in other words, all the troublesome employment related issues that occur in the workplace being bought into the family home. These risks can be managed though and are not a reason to be deterred from implementing this approach.
- It is difficult for parents of people with intellectual disability to be able to formally represent and advocate for the needs of their son or daughter, as Guardians or Administrators. How will this impact on self managed packages?

5 CARER SUPPORT

5.1 If the person with a disability receives a better level of support, including adequate day programs, employment, recreation opportunities and holidays will this improve the circumstances of their carers ?

65% of carers felt that better support for the person with a disability would improve their circumstances. In particular they saw potential for the following:

- Improved ongoing personal care and health support will assist families and carers.
- 'I need in home support and holiday programs for an adult with high needs. I need a holiday, but find it extremely difficult getting in home carers that know my son well enough to do the shifts. A holiday team of carers is needed to get to know the clients prior to parents taking holidays. There are no holiday programs for high needs clients and holiday times are a nightmare'.
- 'It would help to have the person with a disability regularly involved in recreation programs in the evening or weekend'.

5.2 If no, what other separate supports might families need?

Of the 35% who made a 'No' response, the following were concerns:

- ‘The supports above are only the start of what families need. If we are talking about real support it should be education and skill based not just baby sitting. Families need to be moving in a forward direction, no matter how slow, and that means meaningful participation in the community’.
- ‘Some families need assistance in managing people with difficult behaviours. There is little real help for this’.
- ‘Respite and in home support are important when the person with a disability has high needs’.

5.3 What support do carers need to participate in employment?

Carers emphasised a range of needs which reflect their different circumstances:

- Transport for the person with a disability particularly in rural areas to avoid reliance on carers for transport to and from day programs.
- Regular permanent staff for mornings and afternoons to meet centre bus and provide care.
- Vacation care, respite in the home and transport for a person with a disability between home and respite, day programs and school. Currently there is no provision for transport to and from school.
- Prepare employers to respond to the needs of carers.
- Modify the 25 hour rule for parents receiving Carer Payment to encourage their participation in paid employment.
- ‘Financial support at the transition time - our kids take longer to make the transition but they can do it if all parties are a united force pulling in the same direction. Over and above this family carers need support to participate in employment. We are right in the middle of this issue at the moment. Our family should not have to be disadvantaged just because my child needs more support at this key transition time of her life. I could not work for the first 8 years of her life. I have only been able to work 0.8 for the next 7 years and now I am back to 0.3. Why should my family be so disadvantaged? Effectively the lack of support actually compounds the whole impact of disability issue by causing a whole new range of issues including the mental health of the family who has to bear the burden of disability seemingly alone.....and we do feel alone at the moment as we deal with this time of transition in our child's life’.

6 INCOME SECURITY AND CO-PAYMENTS

6.1 Should Carer Payment and Carer Allowance be included as part of a person with a disability’s support package?

85% of respondents considered that Carer Payment should not be included in an individual’s support package, and 70% thought that Carer Allowance should not be included. While most respondents were not in receipt of Carer Payment, they considered:

- ‘It is nice to have the independence of the Carer Payment and Carer Allowance paid directly to me as a Carer. I have to account to VCAT for all spending on behalf of my son and this would add to the amount of accounting I have to do. The payment is to the Carer and should remain separate’.
- The Carer Payment and Carer Allowance are for the carer, not the person with a disability (multiple responses). So is the Carer Supplement. These payments compensate for being unable to work due to caring.
- The carer must have their own support package as their needs are not the same as those of a person with a disability.

6.2 Should the Mobility Allowance be a part of a person with a disability's support package?

70% of carers thought that Mobility Allowance should not be included in an individual's support package. Those against thought:

- 'There is a tendency to 'lose' amounts within a support package payment. The Mobility Allowance in my case pays directly to his day service and I would not like it included with his package'.

Those in favour thought:

- 'Definitely because this squarely comes under the banner of significant impairment. The current aids and equipment service is an embarrassment and this area needs urgent attention - it would make most sense to direct this through a disability support package'.
- 'Not everyone requires a mobility allowance and it should be added on to the disability support package'.

6.3 Do you think it is right that people with a disability aged 67+ will have to make co contributions consistent with the aged care system?

50% of carers found this acceptable and 50% did not. Their mixed views are as follows:

- 'Disability remains regardless of age. Reaching a certain age does not change them or their circumstances and they have far more to contend with than the 'usual' aged person. No co-payments should be needed at any time'.
- 'The criteria should not be the age but the time period people have been supported on a sliding scale. If the 67 year old has been supported their entire life, this should continue. If they have been supported 20% of their life then the co-contribution should reflect this and vice versa. Living with disability impacts on the overall wealth of the family over a long period of time and while the aged care system might lose some money as a result, it is important the family is not further disadvantaged by the person with a disability turning 67!'.
- 'As long as the person has the ability to pay and the payment is minimal'.
- 'I also think there should be means testing for people who are aged less than 67. The financial capacity of the family supporting the person with the disability should be borne in mind. Such means testing will help stretch the dollars put into the scheme by Government just a little bit further'.

7 HOUSING AND SUPPORT

7.1 What are the barriers for people with a disability to access public and community housing, private rental or housing purchase?

Carers thought that key barriers were:

- Lack of public and community housing. Private rental too expensive. Landlords not wanting people with disabilities.
- Discrimination by landlords concerning how the home will be cared for, and adequate finance for rent or purchase.
- Lack of availability and resources! Lack of supported programs. Lack of financial supports. Lack of policies that complement each other across departments.
- Cost and location a long way from services cause problems.

- Inadequate support in housing often causes isolation.
- ‘The barriers would vary enormously depending on the type and extent of the disability. My son who has intellectual and physical disabilities, no speech and chronic sleep apnoea would not be suitable for rental and public housing, and he could not live in his home without a full time carer’.
- ‘I haven't gone through this process myself since my daughter is only 14 but what I do know is that she needs 2 people to care for her (as assessed by Homecare NSW) and her needs are 24 hours a day. I don't know how you would address such intense needs in individual housing’.
- Will families have to pool packages and set up housing options for people who are friends but who don’t need shared supported accommodation? How will this work?

7.2 Should the Productivity Commission address these? If so, how?

Carer responses included:

- ‘I have assumed that the NDIS would cover supported accommodation for all who need it. Anything less would fail to address one of the most critical holes in the current system’.
- ‘Making tough decisions. See the person first and look at the cost second. It is an indictment on our society to see the imbalance that currently exists on the shoulders of carers in supporting disabled family members. It is totally unacceptable that the government is essentially asking carers to carry the burden’.
- ‘Yes, by passing laws on housing access for people with a disability for the whole of Australia which all states must follow’.
- ‘Yes – the Productivity Commission should consult on facts and reality’.
- ‘Consult with real estate industry!’
- ‘Look at the gaps in the availability of suitable housing and make recommendations’.

8 NATIONAL INJURY INSURANCE SCHEME (NIIS)

8.1 Should the NDIS and the NIIS (National Injury Insurance Scheme) be developed separately?

50% of respondents found this appropriate and 50% did not. Carers thought:

- ‘I can see good marketing reasons to do so but, ultimately, the two schemes should merge’.
- ‘I would keep them separate. Those who have catastrophic injury tend to lead vastly different lives to those who are disabled from birth, or intellectual reasons. Their needs are different and they often have a lot of community support from friends and family, which people with a lifelong disability do not necessarily have’.
- ‘For so many years aged care, and those injured in accidents, have been mixed in with disability. They need to be seen as totally different. The care required is different, and the difficulties encountered by people with lifelong disabilities are many and varied. Often families, other than their close family eg parents, siblings - are not supportive of the people with a disability and do not give the extra support required. Please do not see disability in the same light as the aged - which is a natural process - and the injured who often have the ability to communicate and be part of society, which the disabled cannot’.

- ‘People who have an incident that causes an injury to the brain have a complex set of needs. It is often several years before the long term effect of their injury is clear. They do not fit under intellectual disability or mental illness criteria’.
- ‘The two schemes should complement each other’.
- ‘It will be more cost effective to have one governing body. Everyone with an injury needs support but every injury does not cause a permanent disability’.
- ‘There is a need to define catastrophic injury and what timelines are required to establish a permanent disability and eligibility for the NIIS. How will this happen?’
- ‘What about medical accidents? Will these be covered under NIIS?’

9 OTHER COMMENTS MADE BY CARERS ABOUT NDIS

- ‘We must start now as every year we wait the cost to get the scheme up and running is going up and up’.
- ‘Spend some money to save considerably more money. Do not forget the people in the middle (who always seem to get lost). Disability doesn't just happen to the very young and the very old. We are tired of my family missing out. We have done everything possible to provide for our child and give her every opportunity to participate in the community but if she is not covered in the NDIS it will be the straw that breaks the camel's back and I will give up.... put her on the pension, I will give up work completely and look after her at home. We are sick of it all being one way. Treat our family as a special needs family....Be aware that the net is tightly around those who are vulnerable and in need of support and care. In 15 years I have seen many good needy genuine people miss out on support and care while seeing others with lower needs secure more than I would have thought. Be sure the scheme supports the right people and minimise the potential for abuse. Good luck. This is long overdue’.

10 KEY THEMES FROM BROAD CONSULTATIONS WITH 328 CARERS AND 60 SERVICE PROVIDERS

Consultation sessions which were made up of very large numbers of carers and providers focused on more global responses to the recommendations of the Productivity Commission. Participants were briefed about the recommendations and encouraged to express their views.

1. Views about the likely benefits of the NDIS for carers

Perceived benefits included:

- Sustainable funding and future peace of mind for carers.
- Reduced anxiety about the future.
- Less need to beg, plead and justify the need for assistance. No waiting lists. Avoidance of crises.
- Increased dignity.
- Individualised and person centred funding and planning and improved choice for the person with a disability and their family, current and future. Holistic approaches. Choice is supported by information.
- Portability of entitlement between states.
- Independent assessment for the person with a disability and their carer.
- More power to people with a disability and their families.

- Entitlement based on need not labels. End of ‘squeaky wheel’ phenomena.
- Funding from one, not multiple sources.
- Doubling overall funding.
- Promotion of independence for people with a disability (with reduction of demand on carers).
- Promotion of the need for support with transitions.
- Increased flexibility to meet individual needs.
- Training / building capacity of carers.
- Early intervention and access to allied health professionals.
- Streamlined information.
- Single point of contact.
- Access to case management assistance to navigate the system.
- Increased accountability of providers to consumers.
- Cost effectiveness.
- Fewer transaction costs or top slicing of funds.
- A better life for whole families and improvements to health and well being.
- Greater potential for carers to participate in the workforce.
- Potential for support for carers to participate in community life.
- Improvements in employment options for people with a disability.
- No co payments or means testing (> 67).
- Separation of carer needs from those of the person with a disability.
- Common, national assessment tools.
- Improved variety in respite support.
- Access to high quality housing and support.
- Future development of a skilled appropriately paid workforce.
- Emphasis on aids and equipment and travel assistance.
- Systems for complaints and appeals.
- An important research arm of the NDIS.
- Community awareness raising about disability.
- Some family carers emphasised the importance of being seen as people or as a mother, father, sister or brother rather than a ‘carer.’

2. Anxieties and concerns expressed by participants about the NDIS

These included:

- Will it happen?
- Will it deliver and be an improvement? Could it be worse than what we have?
- Will governments guarantee the level of funding needed?
- What scope is there in unit costing for cost increases? For price differences in different areas?
- For people taking on direct employment, who is responsible for OH&S issues?
- Will the broader community be convinced of the need? How to sell it?
- Currently there is insufficient infrastructure to promote choice.
- Importance of local and flexible models of housing and support, accompanied by doubts that the scale of need will be addressed.
- We are old. We urgently need to plan for the long term with certainty. What will happen when older carers die?

- Anxiety about capital for housing development.
- Uncertainty about the eligibility criteria generally, gaps in the criteria and the eligibility of their family member for tier 3 (Autism, psychiatric disability, acquired brain injury, people with moderate disability).
- The need for protection and scrutiny to minimise exploitation and maximise services quality. Self auditing is not appropriate.
- Workforce training, retention and career promotion.
- Services access in rural and remote areas.
- Needs an increased emphasis on the needs of carers.
- Quality of paid carers.
- Evidence based service models and practices not well established.
- Loss of or reduction in Carer Payment.

3. Priority issues raised by participants

The priority issues most consistently raised by participants were, in descending order:

- A variety of models of housing and support to address critical unmet need. This includes the needs of ageing parents, for adults to leave home at an appropriate age and respite. End the crisis driven approach to housing. Ensure planning for future transitions out of home.
- Recognise the needs of carers for support.
- Ensure quality, trained paid workers are available, respected and appropriately paid.

4. What sorts of family situations exist for people with a disability?

Participants listed wide variations in the structures and circumstances of families. These included nuclear families with children, multigenerational families, sole parents, sibling carers after parent death, young carers supporting their parent, sandwich carers, disabled or ill carers, grandparent carers, foster carers, relative carers, step families, blended families, same sex parents, parents of adults (with no empty nest), isolated families, homeless families, and extended families.

5. What supports are needed by carers in different circumstances?

Participants emphasised a wide range of supports that may be needed by individual carers. These included:

- Domestic assistance.
- Behaviour management assistance.
- Advocacy with services providers.
- Respite support including recreation, socialising, community access support.
- Assistance with future planning.
- Case management advice.
- Preventive support – you should not have to relinquish care to get support.
- Timely support when it’s needed. No waiting lists.
- Choice about how much care you can provide.
- Social connection. Community inclusion.
- Long term permanent care for the person with a disability.
- Support through lifecycle stages.

- Continuous support from cradle to grave.
- Support for employment participation. Outside school or centre hours and vacation care.

6. Priority messages from participants about the NDIS

These included:

- Get on with it and get it right.
- Need for intervention now, not in 2015.
- Give immediate attention to unmet need.
- Legislate funding. Ensure it is guaranteed and can't be changed.
- Ensure transparency of funding entitlement.
- Reduce bureaucratic red tape.

11 FEEDBACK FROM DELEGATES TO THE NATIONAL DISABILITY AND CARER CONGRESS 2011

Forty five carers were given limited financial support to attend the National Disability and Carer Congress on 2 & 3 May. This was an acknowledgement of the limited incomes of many carers.

Following the congress we sent 40 of these delegates an online feedback survey using Survey Monkey.

- 65% found all the information presented at the Congress 'very useful.'
- 90% reported that they now know enough about the proposed NDIS to support it. For some delegates questions remain, eg: 'How will people be assessed? Who will and won't be included? How the scheme will work in reality? I can't visualise it.

Narrative comments made by delegates included:

- *'Mixing with other people who either worked in the disability sector or were carers themselves and sharing different experiences. Having the opportunity to attend was wonderful and meant a lot to me as it validated the time and energy I put into caring for my son with an intellectual disability'.*

- *'Many thanks to Carers Victoria for providing us with the opportunity to attend. Only in the last 1-2 years have we become aware of Carers Victoria and how hard it works on our behalf. We hope that we can be of assistance in helping you help us'.*

- *'Many thanks for supporting me to attend this conference. I have already fed back to many others about it and have renewed my passion to advocate for better services and supports for people with a disability and their carers......and the NDIS!'*

APPENDIX 1 – STRUCTURED CONSULTATION QUESTIONS

As used in Survey Monkey and in the Inner Melbourne consultation

The Productivity Commission has released a draft report on Disability Care and Support. Further consultations about the content of the draft report will occur in April. People can submit their response to the Productivity Commission by 30 April.

Eligibility
A person getting support from the NDIS would need to have a permanent disability and meet one of the following conditions:

- Have significant limitations in communication, mobility and self care (225,000)
- Have an intellectual disability (50,000 more) – in addition to those counted above.
    - Some people with a mild/ moderate intellectual disability are acknowledged as eligible as they will need support and assistance with decision making, planning and participation and interpersonal relationships.
- Have a condition for which early intervention would result in an improved level of functioning (80,000) – young children and at onset of condition.
- Be a person for whom intervention would have significant benefits

Question 1: Do the proposed eligibility criteria seem appropriate?

Question 2: Should people with a psychiatric disability who need regular ongoing care and support be eligible?

Question 3: If ‘yes’, what services should be provided by the National Disability Insurance Scheme for this group?

Question 4: If ‘yes’, what services should continue to be provided by the mental health sector?

Initial priorities for an NDIS

The proposed NDIS will take some years to become fully operational. Initial priorities will be new cases as well as those most disadvantaged - including children under 5 with substantial restrictions, people benefiting from early intervention, people cared for by ageing parents and people in nursing homes.

Question 1: Do you think these are the right initial priorities?

Question 2: If no, what other priorities do you think should be included initially?

Needs Assessment
Needs will be assessed through an individual, independent and objective assessment of needs by the National Disability Insurance Agency, the development of a personal plan and its translation into an individual support package. Assessments will consider the ‘reasonable and necessary’ supports people require. Periodic reassessments and assessment at key transition points will occur.

Assessment will consider what support can “reasonably and willingly” be provided by families and unpaid carers – what “natural support” people have available to them.

All of this information will be translated into an individual support package.

Separate assessments are included when caring families provide substantial support. ‘Sustainability and own needs are considered’.

Question 1: Should the needs of all caring families be separately assessed?

Question 2: Should care and support focus on both people with a disability and family carers?

Question 3: Do families need additional intervention and support at key lifecycle transitions such as after diagnosis, preschool to school, school to work,further education or adult day programs, moving away from home?

Individual self directed funding

The Commission recommends individualised funding through person centred and individualised care, rather than block funding to services providers. This is assumed to allow people with a disability and their families greater freedom, choice and control. Support packages will be portable between states. Initially self managed budgets will be limited. Most people will be allocated an entitlement to a package of support and a choice of providers.

Disability Services Organizations will act as agents for the person with a disability and or their family, advise about the choice of available services and broker the package.

Question 1: Is individual self directed funding a good way to go?

Question 2: Will it be a way of shifting power away from providers and governments and towards people with a disability and their families?

Question 3: Do you see any risks in self directed funding?

Carer support

Carer support is defined by the Commission as information and referral, counseling, capacity building/ education and respite.

Question 1: If the person with a disability receives a better level of support including adequate day programs, employment, recreation opportunities, holidays, will this improve the circumstances of their families?

Question 2: What of support for family carers to participate in employment?

Income security and co payments
DSP is not included in the scheme. A cost offset is the objective to get more people with physical and sensory disabilities or mild intellectual disabilities into employment.

The Commission asks for advice about whether Carer Payment, Carer Allowance, Carer Supplement, Child Disability Assistance Payment and Mobility Allowance should be added to an individual support package.

Question 1: Should Carer Payment be included as part of a person with a disability's support package?

Question 2: Should Carer Allowance be included as part of a person with a disability's support package?

Question 3: Should the Mobility Allowance be included as part of a person with a disability's support package?

The NDIS will fund care and support needs of people up to pension age (including age related disabilities). There will be no means and assets test or co contributions. The Commission argues that co payments are inappropriate for people under 67 with a disability as they are less likely to have accumulated assets. No co payments will be asked of families providing informal care although they may be required to pay an initial one off excess payment.

After 67, people with a disability can elect to stay with the NDIS scheme and continue their existing arrangements or transfer to the aged care system and accept its rules. But people 67 + in both systems will be obliged to make co-contributions consistent with the aged care system.

Question 1: Do you think it is right that people aged 67+ will have to make co contributions consistent with the aged care system?

Housing and support

The Commission recommends specialist disability accommodation for some people with a disability. The costs are included in the scheme – and aim for community living in line with community norms. Private rental, public housing and own home (with NDIS provided home modifications and support) are recommended for others.

Question 1: What are the barriers for people with a disability to access public and community housing or private rental or housing purchase?

Question 2: Should the Productivity Commission address these? If so, how?

National Injury Insurance Scheme (NIIS)

Question 1: Should the NDIS and the NIIS be developed separately?

Other Comments

Question 1: Do you have any other comments?

APPENDIX 2 - CONSULTATION QUESTIONS USED IN LARGE CONSULTATIONS

Group responses were recorded on butcher’s paper.

Session 1

Question 1: What are the likely benefits of an NDIS for families and carers?

Question 2: What anxieties or concerns do you have about the NDIS?

Question 3: What do you see as the priority issues for an NDIS?

Session 2

Question 1: What sort of family situations exist for people with a disability?

Question 2: What supports are needed for different family situations?

Question 3: What should be the priorities?