Conversations with Parents and Carers of Children with Disability

Talking about the National Disability Insurance Scheme

November 2012 - April 2013

TAS Carers AUSTRALIA

Background

From November 2012 through April 2013, the Association for Children with Disability (ACD) in partnership with Carers Tasmania asked Parents and Carers of children with a disability a series of questions about the National Disability Insurance Scheme (NDIS).

Three Family Reference Groups were established in the north, north-west and south of Tasmania involving a total of 32 individuals. These Family Reference Groups aimed to provide a clear avenue:

- for families to become familiar with and engage with the NDIS during the development stage and beyond if needed
- for families to have a direct voice into the scheme
- for families to collaborate
- for raising issues and questions
- for gaining information for informed decision making and giving information (families are the best source for information dissemination to other families in the State)
- for the development of ideas, solutions and strategies
- for family capacity building and success when interaction with the scheme occurs
- for a ready stakeholder body for Government access for surveying and information dissemination purposes .

From November 2012 through April 2013, six questions were provided to the Reference Groups by facilitators and individuals were given the opportunity to respond, in person, over the phone, on face book, at meetings, via email and by mail. This report presents a summary of Parent and Carer responses to the questions posed – which are listed below.

The questions

Reference Group participants were asked the following questions:

1. Do you have enough information about the proposed NDIS?
2. In terms of the information that you currently have, what are your thoughts and/or concerns?
3. How do you see the NDIS improving care and support for people with disability?
4. What type/s of support will improve the sustainability of the caring role?
5. What concerns and questions do the information in the NDIS web page fact sheets raise for you?
6. Do you feel your son or daughter has the capacity to exercise the choice and control the NDIS is aiming to provide?

The responses

Not enough information

In response to the question - *Do you have enough information about the proposed NDIS?* - a resounding '*No*' was the answer from all reference group respondents.

Thoughts and concerns about information

Parents and Carers of children with disability were asked: *In terms of the information that you currently have, what are your thoughts and/or concerns?*

Many Parents and Carers expressed concerns about various aspects of the NDIS based on the information that they currently have. It was clear that there was a lot of uncertainty about what the scheme would mean for their situations.

There was concern about accessing information, having the time to read it and understanding the detail about how the NDIS will operate: For example:

> *I am concerned about the wait time for information around the model and associated funding and the presumption that everyone has time to read up-dates on the internet or even have the internet. Updates and information are not getting out at "grass roots level" to key players in a timely manner, making Parents and Carers feel like they do not have a good understanding on how this system will work or if their concerns or queries are being heard. The detail about the NDIS and how it will operate in Tasmania is sparse.*

One Carer was concerned about the potentially narrow scope of the model and the lack of recognition of the social determinants of health and wellbeing:

> *What model will the NDIS follow? I am concerned that we may be following a medical model and neglecting aspects of social inclusion, mental health, mentoring, sporting inclusion that are so vitally important to the targeted trial age group. How will the NDIS bring about workforce and community understanding to enable a needed change to deliver a social model?*

One Carer expressed concern about how to ensure that 'true choice' is an outcome:

I am concerned that individuals will not have true choice of provider unless they or their Parents and/or Carers are able to take on the responsibility and burden for the financial management of packages. The only way to make sure that individuals have real choice is for them to have the control of the money and be able to change providers when wanted.

Some Parents and Carers were concerned about practical issues such as the timeframe, as well as administration processes and its associated costs:

I am concerned that the rushed time frame to set up the NDIS will bring about confusion and negative outcomes for the NDIS Tasmanian client group.

Who will administer the NDIS? I understand that the State Government and Gateway have put a proposal forward that it should be administered through the Gateway, and not a separate body. This apparently will be decided at a Federal level. There is very little information on the NDIS website on what it looks like for Tasmania and each state will probably be very different which may leave issues around a "standard" approach and compliance.

There is concern around the use of funding being dwindled away through the NDIS administration rather than it going directly to the people it was meant for. How much is the administration expected to cost? What additional funds will be available to Tasmanians for the launch?

Others expressed hope for what they would like to see in the new NDIS. For example:

I would like to see more recognition of Carers and the whole family unit and the benefit to society/family welfare system. I would like to see increased services available and support assistance to enable coverage of work hours for those Parents and Carers wishing to seek employment.

I would like to see the NDIS become a 'one stop shop' for assisting people with disability and their Parents and Carers. There are too many places and services to navigate and help is often hit and miss and dependent on who you speak to.

I feel that the NDIS should be launched on a needs basis, not for a particular age group.

One Carer expressed concern that the system will rely on Carers having the knowledge about what services are available rather than the NDIS telling them what options are available:

From information to date on the NDIS I am worried that it will follow the same processes that are currently in place with the Gateways, where it is a "tell us what you need" approach rather than providing users with options available to them. The current system relies on Clients or their Parents/Carer's knowledge of the local services and options available and their ability to navigate them. Will this still be the case?

During the Reference Groups, Parents and Carers reflected on what they believe the NDIS will provide for them and their families. Concern was expressed about it being a 'one size fits all model'. One Carer expressed unease about access to services in rural areas.

I am concerned that the NDIS will not meet the needs of individuals – a one size fits all approach, as are current services (e.g. respite might be available but it's not the kind of respite that caters to the needs of the individual child).

I am concerned that the lack of services and therefore choice in rural areas across Tasmania will continue.

There was also some skepticism and concern about the private sector 'cashing in':

I am concerned that the NDIS will not bring about needed change.

I am concerned that big businesses may see the NDIS as something to take advantage of.

Improving care and support

In response to question three - *How do you see the NDIS improving care and support for people with disability?* – Parents and Carers expressed a range of emotions and thoughts including:

- Concern relating to uncertainty, inequity, timeframes, procedural issues and 'red tape'; for example:

To tell you the truth I really don't know what to expect.

I would like to know now how to make sure that my son will be included in the Tasmanian Launch cohort?

I am more worried now about just making sure my child is registered, will we be included automatically based on age if we are already with the Gateway?

I am concerned that where some in the launch may benefit, others not in the age group will have to wait to receive the support they need. This is not right. We will have to wait and see if things improve.

I am concerned that Parents and/or Carers will have even more to do, as we have been swamped with information in this time of waiting for the NDIS to begin.

I would like to know that people living rurally will have good support providers available to them. If we are waiting on support organisations to build their work force to get ready to do this, how long will we need to wait?

How will we suddenly have lots of great services to choose from? The Better Start program has been going for a while and only has a handful of registered providers in Tasmania. How will the NDIS be different?

I would like to see the NDIS take out the stress of caring for people with disability. Whenever my daughter needs anything there is always heaps of paperwork and red tape to go through. I want to access services with ease.

At the moment we do not have enough ISP hours to cover our needs; an extremely stressful situation. I need to know that the system in place will make sure that I understand how it will work best for me, no guess work.

- Hope for the future and improved outcomes; for example:

Anything that helps me to fulfill my caring role helps my daughter.

I would like to think that people will have real choice of providers as well as be encouraged to change providers if not happy.

- Suggestions for practical ways forward; for example:

I would like to think that service opening hours and supports can be provided to support Carers during work hours.

I would like to see the NDIS take on Case Management responsibilities to assist people with disability and their Parents and Carers.

The sustainability of the caring role

In response to question four - *What type/s of support will improve the sustainability of the caring role?* – Parents and Carers talked about the need for greater recognition and respect for Carers and the roles they play, the need for quality services and better access to information.

- Recognition of and respect for Parents and Carers and the roles they play, for example:

I would like to see more recognition of Carers and the whole family unit and the benefit to society/family welfare system.

The NDIS needs to be clear that it is also about providing care and support to Carers of people with disability. This support will in turn be a way of supporting our sons and daughters with the ongoing care that they need.

I have attended NDIS consultations and I feel that there is a lack of respect and understanding of the Parent and Carer role and the importance of Parent and Carer involvement in the life of our children with disability.

We need a system that shows that it thinks about our role as primary Carers and people in the system that let us know when things are or become available that may support our needs or our children's. We often feel that we are groping in the dark and unless we keep on top of the mountain of information that we may miss out.

- Better quality services; for example:

Quality support options including case management; vacation; in-home; respite; leisure and recreation; and holiday care and assistance to access work and community options, therapy and equipment.

I need good quality support workers who are skilled and a number of support options in case I am not happy with a provider.

If I am given a support package for my son I need to know that I will be able to gain the support hours allocated. At the moment I am lucky if I can get a handful of the 15 hours a week we currently are meant to receive.

Will service provider staff training be paid for out of a support package? My son has very specific needs and people have to be trained before they can support him.

We need service providers who actually will provide the services that they claim to. We need smaller more personalized services.

- Better information and enhanced understanding about the NDIS in general, for example:

I don't even know if I will get the support I need because I have been told that an Aspergers diagnosis will probably not be enough to gain access to the scheme. Is this true?

I need lots of help but first I need help to understand and gain the best from this new system; I really have no idea of what is actually going to happen.

We will need ACD to tell us what we can expect from the NDIS. What is happening with Family Advocacy funding?

Concerns and questions about the NDIS

In response to question five - *What concerns and questions do the information in the NDIS web page fact sheets raise for you?* - the main issues raised by Parents and Carers related to understanding the information and recognising what it means for them and their caring role, as well as simply having the energy to navigate the NDIS space; for example:

To be honest there is too much information and I have given up trying to find the time to read it. We need support from groups like ACD to go through the information and let us know what is important.

We need a cheat sheet with useful facts and perhaps some case studies to show us what to expect. If there already is a cheat sheet we need to be informed of it.

The information is confusing; I have given up reading it.

I still don't know in Tasmania how they will select or prioritize young people to gain access to supports?

Will there be a clear pathway for making a complaint? I am already exhausted.

The life planning process

In response to question six - *Do you feel your son or daughter has the capacity to independently exercise choice and control in the life planning process?* - there were mixed responses from Parents and Carers. Some felt that their child or young person did not have the capacity to be an active participant in life planning processes; for example:

No, my son will be dependent on others in this process.

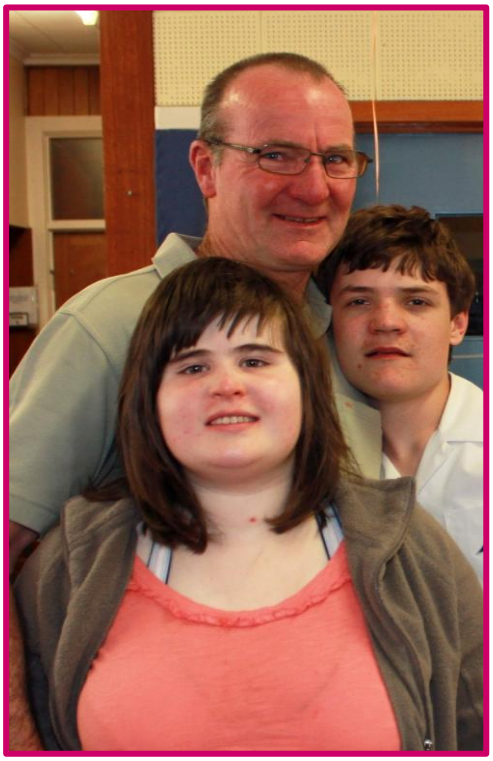
My son lives with us and needs 24 hour care, we are his life planners looking for quality support while we are still alive to assist him.

One Carer explained that the needs of the child were inextricably linked with the needs of the Carer:

If you gave my son choice and control with his planning he would say that he is happy to live at home with Mum forever and would like someone to take him out to concerts and the football sometimes. If you make sure that I have some choice and control I will say that I would like my son to live as other young adults do, in a house of his own (with the support he requires) and in the mean time I would like some Respite so that I can have a night of unbroken sleep, without worrying that my son has had a seizure during the night; and I would like day support hours to be extended to cover usual work hours.

One Carer saw the potential of this notion:

This is a hard question. My son is vulnerable to anyone that is nice to him and dependent on others to give him information so he can make a choice. Perhaps we could include work on this in his plan; I would like to see him reach his potential in this area.



Other issues

Other issues raised by Parents and Carers during the consultation included:

The model
Will a business model be employed, i.e. profit or not-for-profit?

It is interesting that out of the $1 billion allocated for the NDIS, only $342 million actually go to packages for participants. I don't know what normal government wastage is but do you think that's okay?

Will health, allied health, education, personal & community support, employment, transport, respite & accommodation be correlated or interconnected in the new system?

Consultation processes
How many families and Carers were consulted during the process to determine the NDIS model? It seems that many organisations have had a say but that not many of them represent families and Carers or know what families or Carers want. Why isn't it a priority to provide funded support to local organisations, like ACD to communicate with families at the grass roots level?

How Parents/Carers/Family fit in
Where do Parents / Carers / family, fit in to the picture? What will be required of them specifically? Who will help them to navigate this new system?

Priority groups
Will working Carers be a priority for gaining support?

Assessment processes
Who will be the assessment bodies empowered to authorise eligibility for the NDIS?

Can you explain more about the assessment process? How will type of "eligible" disability be determined outside of age and permanent lifelong disability? I.e. congenital, acquired, physical, psychological, intellectual or a combination?

Other Issues (continued)

Quality services
Will the NDIS ensure that they only provide service options to clients for reputable providers who have skilled staff?

Will a list of NDIS registered support providers be collated, including their structure, what they provide, who funds them, who can access them and how, for the use of recipients and will this then be a nationwide standardized registration and process?

What happens to existing services?
If the clients have current support and funding structures in place already through, for example; HACC, Community Access, ISP and Respite, will the new NDIS structure replace what is already there or be in addition to this?

What will the process be to communicate with clients and their families about what they already have in place, what will be available to them in an NDIS and how and what services and supports will transition to the NDIS?

Services in rural areas
What will happen if a Family receives a package but there are no support services available in the area? This is a big problem in rural and remote areas of Tasmania. How will the NDIS change this?

Income implications and financial assistance
For those receiving an NDIS package, what will be the connection, requirements and impact on Centrelink and related income, allowances / tax, etc?

Will the NDIS system enable workers to assist me with things like sorting out Centrelink payments? I have had to try several times to receive disability support pension for my child with Autism and have financial issues regarding assessment as I cannot afford to pay for a Psychologist. Will the NDIS assist with this kind of thing?

Given that this is a National System, will those assessed as having a Permanent disability continue to have to complete other Commonwealth paperwork (e.g. Centrelink) to prove ongoing disability?

I, like everyone else would like to be able to budget and make future and long term plans but pensions and allowances keep changing and don't allow for this. Will the NDIS become yet another system that prevents families from progressing?

In relation to the question about current allowances being affected we would like to know if allowances such as Education and Mobility allowances will be affected by inclusion in the scheme.

Auditing processes and financial management
Will Clients be held accountable or audited for expending NDIS funding? How will funding be reconciled with the client? What options will be available for assisting people to manage funds and will they be expensive?

Other Issues (continued)

Sustainability
How far into the future will funding packages be calculated /allocated? Sustainability is an area of concern.

Will forward projections (planning) be commenced early or mid high school for package planning for support needs for those who will turn 15 in the next year or two?

Advocacy
How can we make sure that Advocacy organisations receive funding?

Truly addressing disadvantage
My son needs 24hrs, 7 days a week care and currently he receives minimal support - 14 hrs a week. Sometimes, due to a lack of local support he can only get 4 hrs support a week, once travel has been taken out. Will we continue to be disadvantaged with an NDIS?

Conclusion

Reference Groups were ceased in April due to the over whelming amount of information being made available to the Parent and Carer cohort and the ongoing confusion about how the system will operate.

There is a need for ACD at this time to redirect its energies and resources into learning about the operations of the NDIS in order to minimise concerns and demystify the system for Parents and Carers.

For the time being ACD will maintain an information only data base for those respondents wanting ongoing email and mail contact and information about the NDIS. ACD will closely monitor the progress of the new system against meeting the needs and attaining positive care and support outcomes of the Parent and Carer cohort and their family members with disability. Assessment of need to activate Parent and Carer reference groups will be ongoing.

About ACD

The Association for Children with Disability (TAS) Inc. (ACD) is a state wide not for profit organisation. Established in 1997, ACD have strived to achieve positive outcomes for parents and carers and their children with disability by provision of , Family and Individual Children's Advocacy, Parent and Carer support, Systemic Advocacy, Information and Education; and Community and Workforce development work across the Tasmanian Community.

Mission Statement

To assist and enable families and Carers to bring about positive outcomes for people with disability in their care.

Vision

Listening and responding to the needs of families and Carers of people with disability.

Motto

'Parents Empowering Parents'

About Carers Tasmania

Carers Tasmania is a non-profit, community based, incorporated association and registered charity. It is the only organisation in Tasmania solely dedicated to improving the quality of life of all caring families living in Tasmania.

Vision

To achieve recognition of the value and contributions of Carers and endorse caring as a shared whole-of-community responsibility.

Mission Statement

To enhance the health and wellbeing of Carers in Tasmania, and promote their rights and needs.

Objectives

- Provide quality Carer-focused services
- Encourage awareness and community support for Carers
- Advocate on behalf of Carers to government and other stakeholders about identified Carer concerns and options for solutions
- Operate a progressive, sustainable, accountable and transparent organisation
- Be recognised as a leader in the provision of support to Carers.

For further information

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