



NDIS FAMILY REFERENCE GROUP SUMMARY
Family Reference Group Feedback November - December (inclusive) 2012



22.2.13 @2.25 PM
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Date	Key issues	Responses
<p>Questions Provided to the Groups beginning:- Friday 23rd November 2012</p>	<p>Questions put to State wide (North, North West and South) Reference Group members (30 individuals in total):-</p> <p>Question 1.</p> <p>1. Do you have enough information about the proposed National Disability Insurance Scheme?</p> <p>Question 2.</p> <p>2. In terms of the information that you currently have, what are your thoughts and /or concerns?</p>	<p>The core responses received from the groups (15 individual responses in total to date from the South and North, with North West comments still to be included following a technical issue with the North West Advocate's computer):-</p> <p>A resounding 'No' was the answer to this question from all reference group respondents.</p> <p>Specific feedback and questions listed below.</p>

Questions and feedback returned on Question 2:

In terms of the information that you currently have, what are your thoughts and/or concerns?

- 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.
- 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.
- 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.
- 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?
- 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.
- 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?
- 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?
- I am concerned that the NDIS will not meet the needs of individuals – a one size fits all, 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 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.
- 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.
- I am concerned that the lack of services and therefore choice in rural areas across Tasmania will continue.

Other queries about the NDIS ?

- Who will be the assessment bodies empowered to authorise eligibility for the NDIS?
- 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?
- 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?
- Will a business model be employed, i.e. profit or not-for-profit?
- Will health, allied health, education, personal & community support, employment, transport, respite & accommodation be correlated or interconnected in the new system?
- 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?
- For those receiving an NDIS package, what will be the connection, requirements and impact on Centrelink and related income, allowances / tax, etc?
- How can we make sure that Advocacy organisations receive funding?
- 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?
- 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?

- 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?
- If the clients have current support and funding structures in place already through, for example; HAACC, 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?
- 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?
- 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?
- 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 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?
- Will the NDIS ensure that they only provide service options to clients for reputable providers who have skilled staff?