National Mental Health
Consumer & Carer Forum

Submission to the National Disability Insurance Scheme

Response to the Consultation Paper: *Supporting you to make your own decisions*

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The National Mental Health Consumer and Carer Forum (NMHCCF) is pleased to provide this submission to the National Disability Insurance Scheme in response to the Consultation Paper: *Supporting you to make your own decisions*.

The NMHCCF is a combined national voice for mental health consumers and carers. We listen, learn, influence and advocate in matters of mental health reform.

The NMHCCF was established in 2002 by the Australian Health Ministers' Advisory Council. It is funded through contributions from each state and territory government and the Australian Government Department of Health. It is currently auspiced by Mental Health Australia.

NMHCCF members represent mental health consumers and carers on many national bodies, such as government committees and advisory groups, professional bodies and other consultative forums and events.

Members use their lived experience, understanding of the mental health system and communication skills to advocate and promote the issues and concerns of consumers and carers.

This submission outlines key issues for the NMHCCF and for consumers. carers and families, in relation to the proposed approach to supported decision making as it relates to people with psychosocial disability.

We would be happy to provide any further information to support the issues raised in this submission. Please contact the NMHCCF via the Secretariat at nmhccf@mhaustralia.org or 02 6285 3100.

Yours sincerely

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Submission to the National Disability Insurance Scheme

Response to the Consultation Paper: Supporting you to make your own decisions

INTRODUCTION

The National Mental Health Consumer and Carer Forum (NMHCCF) supports the overall principles and goals espoused in the Consultation Paper and believes that the content of the paper shows that the NDIS is gaining a greater understanding of some of the core concepts around supported decision making.

The NMHCCF response is focused on the supported decision making for people with psychosocial disability. The NDIS's narrative on supported decision making could be improved by acknowledging some of the unique experiences of specific disability groups, like people with psychosocial disability.

'Psychosocial disability' describes disability experience, impairments and participation restrictions related to mental health conditions which some mental health consumers and families and carers must manage. These impairments and restrictions may include reduced ability to function, think clearly, experience full physical health and manage the social and emotional aspects of their lives. As with other disabilities, the best outcome for people experiencing psychosocial disability will be achieved through access to supports that enhance their social and environmental opportunities to expand their capabilities.

The impact of psychosocial disability with respect to decision making may vary for an individual, including on any one day or across the range of decisions that someone may need to make. The episodic nature of psychosocial disability means that the application of a particular approach will not work for everyone, at all times. It is also important that the NDIS does not assume that everybody with psychosocial disability is a homogenous disability group and that their needs are the same. This is also the case for people with acquired brain injury where a more nuanced approach is required.

Hence the NMHCCF supports the concept of 'Advanced decision-making directives' like an 'advanced care directive' so that a person with psychosocial disability can articulate their desires for supported decision making at different times and situations, when they are well or not, and not just at different life stages.

Information and training are vitally important to ensure supports are skilled in assisting with decision making. The document could benefit from a greater emphasis on ensuring people with lived experience lead development of information and training materials around supported decision making.

Additionally, trust is a crucial component within a supported decision making environment. People with a disability need to develop trust over time with a case manager (not just a support coordinator who only addresses NDIS supports) so that the case manager can understand the person's needs and preferences, in order for them to support decision making. Among other things the current price structure does not allow time to develop relationship to develop this trust.

The Consultation Paper frequently refers to various services being available in the community, but the experiences of NMHCCF members is that these services are often not available or there are barriers to access. Some of the organisations and services mentioned in the Consultation Paper include self-advocacy groups and peer support groups, but these rarely exist for people with

psychosocial disability or even cognitive disability. While there is also mention of ILC funded supports we understand that there is very limited funding for this.

The proposed Action to introduce a formal process around identifying a participant's decision-making capacity is reminiscent of the NDIA's attempt to introduce Independent Assessments. There was much to be learnt from the attempt to introduce Independent Assessments and the NMHCCF would highly recommend that the NDIS not to think too rigidly about decision making capacity, acknowledging the individuality of people with psychosocial disability and the episodic nature of decision making capacity which is dependent on many things, like timing, episodic severity of symptoms, type of decision support/information available etc.

Finally, the navigation and red tape through the NDIS is extreme, with some participants requiring a support coordinator, nominee, advocate, multiple support workers, and also having to work with a NDIS planner, a housing manager, Centrelink worker, social workers, allied health providers and a GP. There is a need for an NDIS-funded Case Manager to assist the person navigate all these services and therefore support them with decision making.

Responses to the Consultation Questions are provided below.

1. How can we help people with disability to make decisions for themselves?

- Keep recovery at front of mind, theirs, and yours. This is the reason they are making supported decisions.
- Encourage them to use their own strengths and abilities.
- Explain, teach and demonstrate SDM.
- Assess decision-making capacity in terms of a spectrum noting the fluidity of capacity across life stages
- By allowing them to have a choice on what is available and explaining the alternatives in a language that they can interpret or understand.

2. Who are the best people help you (or a person with disability) to make decisions? (We call them decision supporters)

- Independent paid professionals and peer workers – reduces conflict of interest and increases participant empowerment
- People selected by the person themselves.
- Support workers
- People who are congruent and empathetic that will take the time to explain all the options in a language that all can understand.
- Family and carers – though this needs to be carefully considered. There is an Increased focus with the NDIS on unpaid, informal supports. This is unfair and unreasonable to the participants as they do not want to rely on family and friends and their goodwill in order for their needs to be met.

3. What should they do to help with decision making?

- Establish 'Advanced decision making' plans and processes when people are well – like Advanced Care Directives
- Actively listen, without judgement.
- Know how to be a supportive decision maker
- By providing options that align with what the person with a disability needs and not what is more about self-interest or gain (i.e., conflict of interest).

4. How can they get better at helping?

- There needs much more focus on education and training of providers to assist participants develop their capacity to make decisions. This training needs to be co- facilitated by those with ABIs, intellectual disability, those with psychosocial disability who have impaired decision making, and their family carers etc. Training programs such as those provided by ADACAS are good examples of what is available: http://www.adacas.org.au/supported-decision-making/supported-decision-making-training/
- Ask the other person "how am I going"?
- By listening to the needs of the person with a disability and their family, carer etc.
- Don't assume lack of capacity and/or nominee is needed
- Independent support and training including NDIA staff

5. How can we make sure the right people are helping? For example: that they are building the capacity of the person with disability, that they are considering what the person with disability wants.

- By taking the time to know the person with a disability and what will help them individually to have more capacity. No-one is the same and they should not be treated as such – we are all unique individuals who have different likes, wants and needs.
- Supporters are included in co-designing their package
- Independent paid support
- Ask the person "who do you want to help with this?"
- And who do you not want to help here?
- Do have the appropriate qualifications?
- Check for vested interests.

6. What should decision supporters know about so they can help people with disability make decisions?

- Be trained (see # 4)
- Understand ethics.
- They should know that the person has a right to self-determination. Guided by their capacity strength's. Where on the spectrum does this individual require support and guidance.
- Understand wants and preferences
- Impacts of disempowerment and how to address this
- Social connections fostered

7. Can you tell us about a time when someone helped you (or a person with disability) to make a big decision? What worked well? What could have been better?

One example:

"Supported decision making with a client to change Psychologist. I read the handover notes provided by the Support Coordinator that I replaced on Maternity leave. In the client's case notes there was a clear request by the client for a change of Psychological support, with substantiated reason. I was able to verify with the clients whilst speaking with them during the process of building rapport. As the clients support coordinator, it is imperative that I act and advocate the clients needs. I obtained consent from the client to correspond with the clients Psychologist, this process is structured as part of the Nominated Primary Professional triage of support which includes a medical practitioner and or Psychologist/Psychiatrist within the provisions of providing mental health support to the client.

What worked well the professional understanding of the psychologist to understand that client/profession match does not always support the clients needs. The Psychologist response was very supportive of the client's needs. The barriers to change were incorporating change at the plan managers level."

8. What is the best way to support people with disability to make decisions about their NDIS plan? This includes decisions about using or changing their plan.

- Know NDIS very well
- Know that they can reasonably ask for and what might not be achieved.
- Have a registration process, similar to that used in the NSW Mental Health Act, to nominate a SDM helper.
- Understand and use the appeals process when needed.
- Involve the other in the decisions as fully and far as they are able to be.
- Use expert resources such as One Door Mental Health and ADACAS (http://www.adacas.org.au/)
- Speaking with them directly, providing alternatives when you are providing support such as reviewing their safety plan and support plan. Being able to discuss these changes with Nominated Primary Professionals (NPP) in a collaborative triage approach.
- Asking the person directly how do they feel about the support they are being provided. Is it adequate, what are they achieving, and are their needs being met.
- Assess decision making capacity in terms of a continuum
- Implementing 'advanced decision making' processes
- Involve people of the participants choosing

9. Are there different things to consider for people with different disabilities or cultural backgrounds? Conflict of interest is when a person or organisation takes advantage of their position for personal or corporate benefit.

- Cultural background will determine who helps, when they help and how a person receives help.
- The method of communication must be effective and appropriate for the persons disability, and best if they choose how the communication takes place.
- Absolutely, culturally appropriate and disabilities backgrounds support need to be understood by a support worker and/or non-Government organisation. Training in these disciplines is very important. It is imperative in providing support for an individual.
- It is very important that we are empowering a person to actively be part of the decision-making process. I have experienced where NGO's due to the client being too complex in their needs and support, want to make decisions as it is more time effective and cost effective to their organisation. The conflict of interest only keeps organisations funded.
- Online tools assume digital literacy and access to devises and internet
- Need to be culturally appropriate
- Accommodate various learning styles
- It is important to acknowledge that people with a disability are not one homogenous group, even if they have the same disability. Therefore, their needs will always be unique.

10. How can we help reduce conflict of interest? Undue influence is when a support person makes the person being supported do something they don't want to do by making them feel scare, by being mean or by threatening or lying to them.

- Suppliers need to declare any conflicts of interest. Failure to do so, if a conflict is later revealed, should allow a supply situation to stop.
- Structural conflicts of interest need to be removed, e.g. no assessments made by a supplier.
- There needs to be an easy open pathway to report any supplier who has a conflict of interest or if they engage any practice that is not good for the client. That reporting needs to be backed up by swift and effective action. The person reporting this needs to know about the outcomes of the complaint.
- Proportionally the NGO's are providing a huge amount of support to individual clients. To help reduce the conflict of interest which incorporates undue influence would be to consider having individual support options that a client could engage in. Such as independent Psychosocial/ Peer Support workers as well as NGO provider options. The clients that engage separately with independent support providers and NGO's could be surveyed to measure any undue influences in comparison to each sector. Making each sector more accountable in meeting the client's needs.
- Give participants choice and control over who supports them and when

11. How can we help reduce undue influence?

- There need to be open transparent and free communication.
- The presence of a chosen and trusted third person can reduce the danger of this.
- Minutes or some approved record needs to be taken and kept. These need to be distributed afterwards to all parties.
- Complaints re undue influence need to be reported independently and dealt with efficiently.
- Introducing competition between independent support providers and NGO's.
- Incorporating lived experience (peer) workforce industry within the NDIS programs.

12. What are your concerns (if any) around people with disability being more involved in making decisions for themselves?

- There is an area of care that sits between dignity of risk and duty of care that needs to be carefully considered. If duty of care is exercised decisions should be supported and enabled.
- If there is considerable unmanaged risk in the decision then advice / action from a suitable third party is suggested.
- The person needs to capacity (with support) to make decisions that support their recovery goals.
- It is imperative that individuals are involved in the decision-making process. It is a valuable tool to learn and that they are provided with every opportunity to build upon the decision-making process.
- When recovery is seen as minimising risk with reference to dignity of risk – this minimises choice and control

13. What else could we do to help people with disability to make decisions for themselves? Is there anything missing?

- Teach all about supported decision making, increase their sense of agency.
- SDM operates in a free and fair environment. NDIS is under a complex set on influences, political and others.
- The intention was stated as a general goal re the NDIS with a view to "cost controls and efficiencies" (Christian Porter, 2016). This intention is being implemented in the following initiatives:
  - An intention to review the 'sustainability' of the NDIS scheme
  - Reduction of the renumerated amounts of certain line items
  - Interference in the operation of the state level NDIS boards
  - Remove 'reasonable and necessary' from the NDIA act.

  As advocates we need to aware of the other influences in the NDIS space.

- Competency assessment and training at each individual level. Empowerment to each individual wants and needs.
  - Education of decision making continuum
  - Build capacity in decision making
  - Explain circumstances that influence decision making (eg. Life stages, decision levels, decision types)

14. Do you have any feedback on our proposed actions in Appendix C of the Consultation Paper?

The Action list at Appendix C (while acknowledging it's not exhaustive) does not seem to make reference to reviewing whether current pricing or support descriptions enable safe and quality supported decision making to be delivered under NDIS plans. I would have thought that was critical to practical action occurring around supported decision making. But perhaps this is something to be addressed in the upcoming implementation plan?

Some specific feedback against each Goal is described below.

Goal 1: Increase opportunities for participants – Agree that there needs to be a Operational Guideline to support decision making for all levels of comprehension, including provision for people who are also culturally and linguistically diverse. Not only will it bring structure and consistency, plus clarity to participants and families, it will also bring those involved with the decision making to account, especially relating to conflicts of interest. Development of a range of materials to support decision making will help with best practice as well as transparency. Business Intelligence tools are good to predict the supports that are needed but should not be the only source used as collaboration with all parties such as through Microboard or Circle of Support can be also quite effective in the decision-making process.

Goal 2: Support development of participant capability – Agree but peer support networks and other individual capacity building supports need to collaborate based on the best interests of the decision maker.

Goal 3: Build capacity of decision supporters – Agree with nothing further to add.

Goal 4: Strengthen support for decision making approach – Nominees – Agree with nothing further to add.