

**10 September 2021**

NDIS Consultation Paper: Supporting you to make your own decisions

Merri Health Feedback

Merri Health creates healthy, connected communities through local health services for people at every age and stage of life. We know that at different times, health needs change. That’s why we support people throughout life, with a range of wraparound services spanning from children’s health to aged care and disability services. We’ve been the trusted health service of local communities for over 40 years. As a not-for-profit organisation, our focus is on partnering with people, responding to local needs, and strengthening the health of entire communities.

Merri Health welcomes the opportunity to provide feedback on the ‘Supporting you to make your own decisions” discussion paper. As a current NDIS Service Provider we have been actively involved in the transition of our disability programs to the NDIS since the commencement of the North-East rollout in 2016, with the majority of our NDIS clients residing in North East Melbourne, or Hume-Moreland. We currently have approximately 550 NDIS clients accessing our services.

Merri Health currently offers the following NDIS programs:

* **MerriKids** (ECEI program for children aged 0-10 years)
* **Support Coordination** (offering coordination of Supports & Specialist Support Coordination)
* **Allied Health** (offering full suite of therapies for adults and school age)
* **Healthy Mind Hub** (group activities for people living with Mental Health issues)

Merri Health currently has a total FTE of 334 and approximately 436 employees. We have 10 sites mostly

within northern metropolitan Melbourne and 1 site in regional Victoria, where we deliver our Victims

Assistance Program (VAP) and work with the NDIA as a partner in the community for ECEI in the Ovens

Murray region.

**Key discussion questions**

We have answered these questions from the perspective of a service provider using a person-centred approach and drawing from our experience supporting vulnerable clients under the NDIS.

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

* Ensuring information that is required to make a decision is presented in the participants preferred format and language, and is accessible and understood, for example, culturally appropriate and easy to understand (easy English in some circumstances)
* NDIS plans need to be adequately funded for service providers to be able to take the time to develop rapport and trust with the individual, and to identify their value system, likes and dislikes and what they want for their life. This will also allow for the time needed for people with a disability to be supported in their ability to weigh up the pros and cons of a decision and make informed choice.
* Acknowledgement that the process for making decisions for people who identify as CALD is unique; for example, providing out of home respite options or moving out of home for someone who has just turned 18 years old may not be acceptable in some cultures. Ongoing consultation and engagement with representatives from CALD groups is required to ensure the needs of these groups are met. Planners, LAC’s, Support Coordinators and other service providers may need additional cultural specific training to better understand the needs of people with a disability who identify as CALD.
* Investigate and clearly document what a person with a disability doesn’t want. This can be just as powerful as what is wanted, and should be done is such a way that it does not confuse the decision making process, illicit an unwanted emotional response or make the person feel overwhelmed.
* The NDIS to determine and clearly document the individual’s capacity to make decisions at the start of the NDIS journey. We believe this should be determined by a panel of professionals with specific assessment skills in this area such as a Psychologist, Social Worker, Allied Health professional and/or Medical Practitioner. At this stage if the person has been identified as having the ability to develop capacity in decision making then this needs to be a focus of their NDIS plan and be appropriately funded and reviewed regularly (perhaps at plan review meetings).
* Service providers need to be provided with opportunities, resources and funding to attend training on how to support people with a disability in the process of decision making. We believe it is the responsibility of the NDIA to provide regular training opportunities.

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

* We felt it was important that the decision supporter be knowledgeable about the NDIS and the supports available as well as the interface with mainstream services. Support Coordinators would be very suitable to assist with decision making and fulfil the role of decision supporters.
* We also understand that not every person will be funded for support coordination. In this instance we recommend identifying an alternative person where there is no apparent conflict of interest, motive for financial or personal gain and who has the time, knows the person with the disability well, and has knowledge of the NDIS. This could be a family member, friend, disability advocate or a person who has been objectively determined to be suitable by either the NDIA or other relevant organisation such as the office of the public advocate. The person with the disability and their family/carers should be actively engaged in this process.
* It has been our experience that a high proportion of NDIS participants are appointed plan nominees when the participant’s capacity to engage in supported decision making has not been assessed and determined. Many of these participants would be better suited to a correspondence nominee as this would allow the participant to participate in decision making and likely make the process of making decisions about their supports and implementing their plan more timely, person-centred and efficient.
* Independent advocates who understand the NDIS and the disability sector would also be appropriate for this role. It has been our experience that this option has only been available to people with a disability that do not have informal supports and is time limited, which means rapport and trust is not developed. Advocacy agencies need more funding and resources.

In summary, an ideal decision supporter would be a person who has an understanding of supported decision making, understands the NDIS, interfacing mainstream services and the disability sector as a whole, and most importantly has a time and desire to be a decision supporter.

1. **What should they do to help with decision making? (the decision supporters)**

It is our belief that the decision making ability of a person with a disability needs to be more clearly defined by the NDIS and we are in full support of the proposal to implement a Support for Decision making policy and framework within the NDIS.

In order to help with decision making the decision supporters should:

* Have the time and resources (funding if needed) to adequately undertake the role
* Spend time getting to know the individual and understanding their needs/desires
* Have the appropriate training and awareness of what the role entails
* Be clear about the areas of a person’s life they can assist with and those in which they can’t

1. **How can they get better at helping? (the decision supporters)**

We believe the appropriate skills and training is crucial and we recommend the decision supporters complete a training module with a competency based assessment to ensure they have the skills and ability to fulfil the role.

This training module should provide:

* awareness of current legislation and scope of practice
* clear boundaries and information on what areas of the person’s life they can assist with decision making
* practical information and tools on how to build the decision making ability for a person with a disability and how to monitor and review
* introduction of an assessment tool that can be used to monitor and revaluate the changing nature of a person’s decision making ability and a clear process around what to do when this is identified
* information about dignity of risk and the right of the person to make their own decisions even if these are perceived as poor decisions by the people around them

In summary, we believe clarity is required around determining the participant’s capacity for decision making and clarifying the point at which a decision supporter needs to step in to help. As suggested earlier in this submission, we believe the NDIA should implement an objective assessment panel to assess and provide recommendation on a participant’s decision making capacity. There also needs to be clear guidelines around where the responsibility of a decision supporter starts and where it ends, for example, a participant may have the ability to decide what clothing to buy but need support to make bigger decisions about where to live.

1. **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.
* Ensure the decision supporter understands conflict of interest and includes the person with the disability in decision making. We have seen this repeatedly with our clients where family members who are plan nominees or guardians make a decision based on what is best for the family unit and not the family member with the disability, therefore bypassing the opportunity for the person with disability to participate in the decision making process. This has also been evident in some instances where service providers have automatically made the assumption that a person with disability will want to access all supports from one service provider, often influencing the person with the disability to make this choice. We recommend that decision supporters undergo additional training in this area and an appropriate screening process be implemented to ensure decision supporters are aware of conflict of interest.
* The values and beliefs of the decision supporter should align with the person with the disability. We are suggesting that the arrangement between decision supporter and the person with disability be flexible and have a trial period to determine if it is working. Effective mechanisms should also be put in place to ensure the person with disability has the opportunity to provide honest and transparent feedback prior to a more permanent arrangement being made.
* It should be acknowledged by the NDIS that some participants may not have any capacity to improve their decision making ability and that their capacity may reduce over time e.g. those with degenerative conditions or complex mental health issues. Where this is identified the decision supporter needs to have awareness of this and understand the additional responsibility, complexity and importance of decisions they will be making on behalf of the person with a disability.
* Objectively measuring improvements in a person’s decision making capacity is a complex exercise that will require the development of assessment tools, specific guidelines, and training and education of the decision supporter. We can therefore assume that the decision supporter will need to be highly skilled and competent in supported decision making and this may be beyond the scope of unskilled workers.
* In the absence of a Support Coordinator it is recommended the NDIS be transparent with information about who is central to a participant’s everyday life and make this information easily accessible to service providers (with consent). This will ensure barriers of communication between multiple service providers are removed and service providers can work in collaboration to identify and measure improvements in supported decision making across all of the participant’s life domains, adopting a holistic approach with the best collective outcomes for the person living with disability.
* We recommend that the NDIS ensures the criteria for measurement of improvement (or success) with supported decision making be based on quality of life indicators and not on the cost of supports needed to support a person with a disability (i.e. the decreasing or increasing value of their NDIS plan).
* We suggest the NDIS embark on a broader national community education strategy around supported decision making as there will be regional differences and nuances. This means engaging with local communities and educating people in the disability sector and relevant mainstream services about the process for supported decision making.

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

* Federal and state government legislation and legal responsibilities relevant to the person living with disability.
* Decision supporters need to be mindful of bias, particularly subconscious bias that may relate to their personal beliefs/values, to ensure this does not influence decision making for a person with disability.
* It is critical to look at the person with disability holistically and to develop a thorough understanding of the person’s dreams, desires, likes and dislikes.
* Decision supporters need to be aware of the time commitment required as supported decision making can be complex and time consuming and ensure that they have adequate capacity to undertake this effectively.
* They also need to have an understanding of the NDIS and the different types of disability, human rights and dignity of risk and how this can affect decision making.

1. **Can you tell us about a time when someone helped a person with disability to make a big decision? What worked well? What could’ve been done better?**

A Merri Health Support Coordinator was working with a participant with advanced stage Multiple Sclerosis who presented with cognitive decline and reduced ability to communicate. Her husband is her sole carer and legal guardian and they both live together in the family home. Both are from CALD backgrounds and have limited understanding of English and the Australian health care system having not lived in Australia for an extended period of time.

The husband was faced with making a difficult decision about whether to proceed with the second stage of a medical procedure. His wife had experienced an adverse reaction to the first part of the procedure which was life threatening and as a result had to be hospitalised. He did his best to weigh up the pros and cons and think about what she would have wanted however he was still undecided and didn’t want to make a decision based on emotion but one on medical facts and advice. He sought out the advice of the medical professionals involved in his wife’s care in the hospital. This is where he encountered an issue; the medical professionals would not provide him with the medical facts, evidence and advice needed for him to be able to make an objective decision. In the country of their origin, he and his wife were conditioned to respect and highly regard the advice of medical professionals and he could not understand why they weren’t helping him. With limited English and reduced ability to find the right information he was anxious about what the next step would be and shared this with his wife’s Support Coordinator. The Support Coordinator felt the situation was complex and felt out of her depth to help him however what she did do was assist the participant’s husband to find the information he needed and was mindful of her professional boundaries and refrained from giving the husband her opinion about what to do. The Support Coordinator also provided him with strategies to assist with how to reflect on what his wife would want to do. He finally had the information and the strategies required to make an informed decision about what the next step would be in his wife’s medical treatment.

In conclusion, having a highly skilled and experienced Support Coordinator who understood the complexity of the situation, had the time to do this (not unfunded), understood the cultural sensitivities and her professional boundaries greatly assisted in supporting an effective decision making process. One aspect of the process that could have been improved was the interface between disability and mainstream healthcare services. If this was better defined and the medical professionals clearly understood their role, this could have alleviated a lot of anxiety for the participant’s husband.

1. **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.**

* Provide information in their preferred medium, format and language. We recommend the NDIS develop additional resources and make them readily available to participants and service providers.
* Connect them with appropriate decision supporters who understand what is involved in fulfilling this role and ensure their values and beliefs align with the person with the disability.
* Service providers need to be equipped with appropriate funding to be able to spend the time supporting people with a disability to understand their NDIS plan. From our experience Support Coordinators and allied health professionals have been predominantly undertaking this role in the sector without funding. This leads to financial losses and impacts long term viability for some providers to deliver NDIS services ethically whilst remaining financially sustainable.
* On-going consultation with people with a disability about what they want is also important. This could be in the form of focus groups and/or other similar face to face gatherings. Although submissions from service providers are valuable, the perspective of the person living with disability should also be distinctly sought out and considered.
* Consideration by the NDIA about how to gather feedback from highly vulnerable and isolated members of the disability community who may not be able to provide feedback. We believe there is a lot of value in the information from these individuals.

1. **Are there different things to consider for people with different disabilities or cultural backgrounds?**

* We have concerns for people with a cognitive or intellectual disability and their ability to understand the information provided to them; service providers and decision supporters need guidance and education around how to be effective information sharers.
* This cohort group requires an additional layer of protection as they are susceptible to abuse or scams where the central support people in their life can misuse their funding. Therefore the person (s) assisting in the decision making process need to have a genuine motive and have the best interest of the person with the disability in mind.
* People from CALD backgrounds may have lower English literacy levels and a more limited understanding of the Australian health care system. This can affect their ability to make decisions and should be considered to ensure barriers for communication are effectively addressed.
* It is important to acknowledge many people may have limited ability to use technology and access information online and from the internet, not all people with a disability have the skills and resources to access information in this way.
* Information needs to be presented in different formats and languages by the NDIS, service providers will need guidance and resources from the NDIS about how to do this. A strategy needs to be implemented that facilitates easier access to interpreters, there are barriers at present.
* Having a thorough understanding of the different cultural expectations of people from different CALD backgrounds is critical when making important life decisions. For example, the decision to move out of the family home may not be a rite of passage for a young person aged 18 years of age in certain CALD communities and the use of out-of-home short term accommodation may not be culturally accepted.

1. **How can we help reduce conflict of interest?**

* Be open and transparent about the potential for conflict of interest, as it relies on the person with the conflict of interest to disclose this to the person with a disability.
* Provide a better understanding of what constitutes conflict of interest, including clear definitions, examples, and education provided to people with a disability, their carers and family, and service providers.
* From our experience some providers can be aggressive in their sales approach and actively interfere with the process of people with a disability making decisions about who will provide their supports. We have seen this particularly with vulnerable people living in supported residential services (SRS) where one provider monopolises and signs up all the participants living at the one site. We believe there should be harsher penalties and consequences for this type of behaviour e.g. investigation and de-registration etc.
* We recommend the NDIS commission have more oversight over conflict of interest and implement a simpler and more efficient process for reporting instances where this occurs. We are aware of incidences where service providers are breaching conflict of interest and don’t stop this practice as there aren’t repercussions and the penalties are not harsh enough.

1. **How can we help reduce undue influence?**

* Greater education, awareness and monitoring of the practice of undue influence for service providers, supported decision makers and the disability sector as whole. This may need to be a part of a broader community education program to highlight the importance of eliminating this practice.
* Improve the process for reporting this behaviour; a simpler and clearer process is required with significant repercussions, particularly for repeat offenders.
* Introduce a mentor or coaching program for service providers or decision supporters who have exhibited undue influence in their practices. We believe the notion of undue influence can be a complex area with shades of grey which may require on-going support in order to improve understanding and behaviour.
* Making people with a disability, carers and their families aware of what their rights and responsibilities are in regard to supported decision making and what external parties can ask and not ask of them. We believe simple and meaningful case examples in different formats would assist with education around this.

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

* If people with complex disabilities are not provided with the right support and skills for decision making, they may end up not comprehending or understanding information due to the executive reasoning skills required, and may not be able to weigh up information to make informed decisions.
* People with a disability are vulnerable, we are concerned that they will not understand the impact of their decisions and be taken advantage of emotionally and financially.
* The potential for people with a disability to feel overwhelmed by the whole process of decision making, and not have the appropriate support structures around them which may have a negative impact on quality of life.
* We believe capacity building around decision making for a person with a disability is complex, gradual and requires time and resources. Our concern is that this will not be a process implemented by the NDIS, interfacing mainstream services and disability service providers.

1. **Do you have any feedback on our proposed actions in Appendix C of this paper?**

Overall, we believe the proposed actions for the Support Decision making framework are well thought out, inclusive of the broader community, and innovative. We do wish to acknowledge that the type of change alluded to in the consultation paper and proposed framework will involve big shifts in the way we approach supported decision making and will require a large cultural change which will take time and resources to achieve. We look forward to seeing how this will unfold in due course.

Proposed feedback on Appendix C:

* There is significant reliance on informal supports – friends, families and carers of people with a disability may not have the time or desire to do this. Also, a significant number of people with a disability are isolated and alone and may not have informal supports.
* Ensure there is meaningful engagement with, and education of, the disability sector and broader community as well as mainstream services.
* Information is required on what the interim process will be for supported decision making while these larger proposed changes are implemented.
* More information is needed on the evidence and models of practice that underpins these recommendations and how the outcomes will be measured.

For any further information on any aspect of this submission please contact:

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**Support for Decision Making consultation submission**

**Name:** Merri Health (VIC)

**Date and time submitted:** 9/9/2021 4:05:00 AM

# **How can we help people with disability make decisions for themselves?**

* Resources: No
* Information: No
* Decision Guides: No
* Having a person help: No
* Other: No

# **Who are the best people to help you (or a person with a disability) to make decisions?**

* Family: No
* Friends: No
* Peer Support Networks: No
* Mentors: No
* Coordinators: No
* LAC: No
* NDIA Partners: No
* Advocates: No
* Service Providers: No
* Other: No

# **What should they do to help with decision-making?**

see attachment

# **How can they get better at helping?**

* Getting to know the participant well: No
* Doing some training on decision support: No
* By having resources and information about providing decision support: No
* Other: No

# **How can we make sure the right people are helping?**

* They are chosen by the NDIS Participant as a decision supporter: No
* They value the rights of people to make decisions with support: No
* They are a registered provider: No
* They enable the participant to take risks: No
* Other: No

# **What should decision supporters know about so they can better help people with disability make decisions?**

* Guidelines for decision supporters: No
* Scenarios or Examples: No
* Information Sessions: No
* Support Networks: No
* Other: No

# **Can you tell us about a time when someone helped you (or a person with disability) to make a big decision?**

No answer recorded

## **What worked well?**

No answer recorded

## **What could have been better?**

No answer recorded

# **What is the best way to support people with disability to make decisions about their NDIS plan?**

* Practice: No
* Peer Support Networks: No
* Information and Resources: No
* Guidance Tools: No
* Not Sure: No
* Other: No

# **Are there different things to consider for people with different disabilities or cultural backgrounds?**

**An intellectual disability:** No

**A disability that impacts how they think, a cognitive impairment:** No

**A psychosocial disability:** No

**A disability that impacts their ability to communicate:** No

**From a CALD community:** No

**From an Aboriginal or Torres Strait Islander Community:** No

**From the LGBTIQA community:** No

# **How can we help reduce conflict of interest?**

see attachment

# **How can we help reduce undue influence?**

see attachment

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

see attachment

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

see attachment

# **Do you have any feedback on our proposed actions in Appendix C of the paper?**

see attachment