

9th September 2021

# Consultation Paper: Supporting you to make your own decisions

Thank you for inviting submissions to provide feedback on the Consultation Paper. Our feedback focuses on our experiences with families of young children and was based on a survey of the consultation questions completed by our team.

We congratulate the NDIA for a strong paper and for incorporating a whole of life approach. We suggest that this broader approach be incorporated in all aspects of the NDIA to ensure that the scheme is relevant for young children and their parents.

**About Plumtree:**

Plumtree is a not-for-profit organisation that provides support for young children aged from birth to 8 years old with a developmental delay or disability and their families.

Operating for over 30 years and based in Marrickville, Sydney, our vision is for a society where children with disabilities and developmental delays, and their families, are supported to have a full life in the community.

Our team have expertise in early childhood development and are passionate about working with children and their families. They are a culturally diverse team and include therapists, educators, therapy assistants and peer workers.

**Our feedback**

We firstly offer some general feedback about the paper and secondly, we provide feedback from our team in response to the submission questions.

**General feedback**

We suggest that the lifespan approach outlined earlier in the paper be strengthened throughout, by consideration of the following suggestions:

* In 3.2, mention could be made on the UN Rights of the Child
* On page 7, consider including the point that parents and carers of young children would benefit from opportunities to understand how to make better decisions.
* On page 7, consider inclusion of early education settings and school among the transitions mentioned.
* In 4.1, consider including reference to the life span approach as a key principle starting from early childhood and that families are the key decision makers in a child’s life until they are 18 years old.
* In 4.3.1 Life Stages, consider adding parents in addition to adults as key decision makers for children up to 18 years old.
* Figure 3 explains the life stage approach very well from the perspective of the participant including children. However, consideration could be given to the capability of parents to improve their decision making as well since they will be making a significant amount of decisions for their children from birth to 18 years.
* We offer a model in Figure 1 which may be of assistance in explaining the role of parents in building their child’s decision-making skills throughout their childhood. For more information see [https://plumtree.org.au/blog/a-child-voice-model-forchildren-with-disabilities-to-thrive-in-the-future/](https://plumtree.org.au/blog/a-child-voice-model-for-children-with-disabilities-to-thrive-in-the-future/)



Figure 1. A child voice model (Mahmic and Janson, 2019)

**Submission questions**

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

Our team explained that firstly, parents are the main decision makers in the child’s life. Helping parents to make decisions for themselves is a shared process in the early years that aims to empower parents. This is achieved by a family-centred approach in which they listen to the needs, wants, values, and preferences expressed by parents. They provide parents with information and help to understand their options so that they can make the best decisions for their child and family. They must convey that they value the parent’s choices.

Secondly, staff described the importance of helping parents to understand their role in building their child’s decision-making skills by starting small and allowing children to increase autonomy as they grow. Above all, a strengths-based approach was valued through following a child’s strengths and interests:

*I am ultimately led by the parents’ blueprint for what would make their child truly live their happiest life. Starting with this ultimate goal and then scaffolding any support around that blueprint would support happy, full, fun, meaningful lives for children.*

*Recommendation: Recognise that parents of young children birth to 18 years old are the main decision makers for children and that there is shared decision making with professionals and their child to varying degrees at different stages.*

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

Parents in the early years benefit from support to make decisions through a collaborative approach with input from a team that includes people who are trusted and known by the family and who have their interests at heart. This includes the child’s natural support network including parents, siblings, extended family, friends, community, early childhood providers, including early childhood education and early intervention providers.

Our team viewed parent peer workers as offering a valuable and complementary role to help families gather information in order to make good decisions. In particular, trained parent peer workers who were able to convey a strengths-based approach by developing a:

 *cycle of possibility thinking where developmental growth of the child is supported and celebrated, which allows seeds of more possibility to sprout, people believe in possibility when possibility is encouraged.*

*Recommendation: Shared decision making in the early years occurs through a collaborative approach with input from both formal and informal supporters, including parent peer workers, and should be strengths focused.*

1. ***What should they do to help with decision making***

First and foremost, our team highlighted that the Early Childhood Early Intervention partners should lay foundations for shared decision making with the families in their early connections with them. Doing this will set an expectation that parent participation in decision making is positive and desirable. This will counter the tendency of parents to defer to professionals by alternatively, creating an expectation of partnership and collaboration. The team saw that the benefits of this were that parents will be more confident about making choices that suit their family and be more able to resist pressures to make choices that do not suit their family.

*Recommendation: The expectation for shared decision-making should be laid in the family’s first experiences with the ECEI partner.*

1. ***How can they get better at helping?***

Help giving practices that build the capacity of families are foundational in familycentred practice and staff responses focused on aspects of these practices. These included knowing the family and listening to their needs, strengths, and dreams in order to build the knowledge, skills and capacity of parents to make decisions for themselves. This included understanding how to hear the child's voice in order to nurture their independence. Above all practices and processes which build the participation of families are paramount.

Overall, staff suggested better awareness of best practice principles as described in the national document 2015 available at [https://re-imagine.com.au/practitioner/what-isbest-practice/.](https://re-imagine.com.au/practitioner/what-is-best-practice/)

*Recommendation: The NDIA to promote capacity building family-centred practices which are central to early childhood intervention.*

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.***

Our team said that the right people are those:

*that want to see the young person flourish and therapists should be aiming to do themselves out of a job.*

The right people are those who promote the importance of capacity building, familycentred practice, and the use of a key worker model which support families to understand and choose the right decision supporter for them. Training on familycentred and person-centred approaches were considered by the team to be helpful to create the right kind of helpers. The promotion of decision-making tools or aids was viewed as an indicator that the right people were helping. Our staff felt that it was important to convey to families how they can identify the right helpers:

*Look for signs that they are taking the participants wishes into account and if they make decisions based on decision making tools that keep the child and family at the centre of the process, including the child’s strengths.*

*Recommendation: Support families to identify the right type of help so that they can identify people who will use various decision-making tools that will enable them to make better decisions.*

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

 Our team believes that ultimately parents should be supported to create the best life for their family.

*Agency, teach them Agency. Let's face it, parents are entering a world they know little about and are in a state of stress, worry and overwhelm where they hand over their natural authority and power (unwittingly) to the medical professionals.*

Decision supporters should have a relationship with the family, so they have a clear idea of the child and family situation, cultural issues and their capacity including their preferences, strength, dreams, supports, needs, communication style, including how to make information accessible. Decision supporters should also respect the right of the family to make decisions that may not reflect their own perspective.

Decision supporters should also understand the rights of families and children to be a part of the community because current barriers to inclusion are a reality for parents and they need support to navigate their way through these barriers.

*Recommendation: Decision supporters should be knowledgeable about the human right-based approach and work in a strengths-based way to help parents navigate their decisions.*

***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?***

Our team recommended coaching strategies to understand the parent's needs, values, purpose, preferences and use this knowledge to provide information about options. That is, supporting the parent as they took on the information to make a decision that was right for them in partnership with professionals as illustrated by this experience:

*Our child was not able to walk, and a natural progression was that we would trial a walker and use that tool as a support to help our child become mobile. Our child is very determined and tries very hard with their gross motor development. The day of the trial came, and our child fought the walker, refusing to use it and not participating at all in the session. Our usually very active, happy child was rebelling. Even though our child is non-verbal, we listened and together with our child's physiotherapist made a brave call that a walker was not for our child. They were telling us this and we were listening. Recently, our child has started to take independent steps on their own terms, no walker, just their way. We believe that our child is making choices regardless of their disability and we need to listen and read their signs for what are the best options for them.*

Building confidence and understanding of the rights of children with disability was also seen as helpful to make decisions:

*Thankfully there have been many times I've been supported! I was encouraged to take my daughter out of a special unit in a school and take her to the mainstream, all while the Principal of the school was advising me against it and telling me that the special unit was the best place for my daughter. What worked well was the person told me to trust my instincts as a parent, they told me to not listen to the doubters, but to "give it a crack", what could have been better was that this person was unable to say this in any meetings because they were employed in the school and be at odds with what 5 others in the meetings were saying. One of the single best things we ever did for our daughter was to place her in mainstream school, she has a intellectual disability but is thriving at the school... she is learning so much from both teachers and students, and dare I say perhaps teaching them even more!*

Finally, staff recommended our bespoke planning tool, Pictability, as a way for parents to participate more in planning by thinking about their goals using a visual game-like approach, to articulate their desires and hopes, rather than a traditional planning

meeting. For more information [https://plumtree.org.au/plumtreecommunity/pictability/](https://plumtree.org.au/plumtree-community/pictability/)

*Recommendation: Build systems that support the skills, confidence, participation and agency of parents to make good decisions within a human rights based framework.*

***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.***

Our team believed that advice from multiple sources helped parents to make decisions about their NDIS plan. This advice could be from trusted professionals, knowledgeable parent peer workers, or other parents who had experience with the NDIS. For some families, having a support coordinator would also be helpful.

Funding flexibility and simple NDIS processes were also seen to be a helpful way to encourage parents to make decisions about their NDIS plan so that they could have a more holistic approach to planning supports that support their child in the community:

*Ultimately it would be more beneficial to provide plans that you could move funding between buckets as needed.*

*Recommendation: Decision making is improved when there is an environment from which a variety of people can be chosen for decision support.*

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

Our team believes that every situation is unique, and they listen to work out how best to support an individual. Parents from culturally diverse backgrounds may need more support due to the intersectionality of disability, language barrier and culture. Cultural sensitivity should also be considered when looking at the person's needs and preferences/background. Different communication and information processing styles must be considered so that information is accessible. The value of knowledgeable friends and cultural peer networks was seen as helpful:

*I got a good friend to help me with the NDIS review for my niece. The friend speaks good English and has lots of up-to-date information about NDIS funding. My friend checked with me what documents I have sent to NDIA to get the funding. For example, I forgot to attach the report of the pediatrician that had all the requests and recommendations for NDIA. So, she told me that’s important I must do it this time for the review. Things could have been better if I sought her help in the first place so it would have saved me time and disappointment.*

*Recommendation: Greater awareness and sharing of resources amongst decision supporters so that they can better support people from CALD backgrounds, including strengthening CALD networks.*

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

Our team viewed the role of the NDIS Quality and Safeguarding Commission as being central to creating systems to reduce conflict of interest. Furthermore, they believed that being a Registered NDIS Provider of Supports provided a mechanism to reduce conflict of interest as this required regular auditing, commitment to continuous improvement, and ethical behaviour when working with families. They identified that creating an environment where there is absolutely no conflict of interest is unlikely and so believe that encouraging families to engage with NDIS registered providers is currently the most effective way to address this issue.

The team also believe that team approaches are a mechanism to reduce conflict of interest. In particular, they recommended that staff should be trained in person/family centred approaches.

*Recommendation: Strengthen and promote the use of team approaches in early childhood intervention and encourage use of NDIS Registered Providers.*

1. ***How can we help reduce undue influence? Undue influence is when a support person makes the person being supported do something they don’t want to do by making them feel scared, by being mean or by threatening or lying to them.***

Our team suggest that a human rights-based approach is central to reducing undue influence. This would make it clear that the participant has a right to make decisions. Once again, a team approach was seen as protecting against undue influence. Quality supervision of teams, connection with other families and building family capacity were also seen as ways to reduce undue influence:

*I strongly feel that educating parents about their parenting role EARLY in their families disability journey is the best way to set them on a better path, one with a framework they can follow, one they don't have to discover on their own.... and one that can guide them to not only best practice principles but to also guide their thinking to remain focused on their child’ outcomes for independence.*

*Recommendation: Clearly convey a human rights-based approach from the start of a family’s experience with the NDIS.*

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

Our team expressed concern that parents were more vulnerable in the early stages of their experiences due to their tendency to defer to professionals as they were new to the disability supports system and still learning. Our team identified a number of concerns in the current system that posed a risk to parents making good decisions. Firstly, parents may not be accessing the supports that they are entitled to because they are unfamiliar with what is available to them due to the complexity of the scheme and not being able to get a clear answer about what is possible using their funding.

Secondly, they may be asked to make big decisions straight away without being given capacity building supports to learn decision-making skills.

*Recommendation: Consideration be given to better supports for parents at the beginning of their journey.*

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

Our team suggested the following other practical suggestions:

* + Have information and examples on the NDIS website of what participants have used their funding for, besides individual therapy sessions
	+ Provide funding for translation of information into formats.
	+ Support more courses/workshops/learning of how the NDIS works and the rights of each participant.
1. ***Do you have any feedback on our proposed actions in Appendix C of this paper?***

A targeted approach for complex groups where there are multi-faceted needs would be welcome. This could provide more proactive information and guidance to support these groups and build their skills to participate in decision making.

Yours sincerely,

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**Support for Decision Making consultation submission**

**Name:** Plumtree Children's Services (NSW)

**Date and time submitted:** 9/10/2021 6:55:00 AM

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

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

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

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

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

No answer recorded

# How can they get better at helping?

* Getting to know the participant well: Yes
* Doing some training on decision support: Yes
* By having resources and information about providing decision support: Yes
* 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: Yes
* They are a registered provider: Yes
* They enable the participant to take risks: Yes
* Other: No

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

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

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

Yes

## **What worked well?**

see attached

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

see attached

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

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

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

**An intellectual disability:** Yes, See submission

**A disability that impacts how they think, a cognitive impairment:** Yes, See submission

**A psychosocial disability:** Yes, See submission

**A disability that impacts their ability to communicate:** Yes, See submission

**From a CALD community:** Yes, See submission

**From an Aboriginal or Torres Strait Islander Community:** Yes, See submission

**From the LGBTIQA community:** Yes, See submission

# How can we help reduce conflict of interest?

See submission

# How can we help reduce undue influence?

See submission

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

See submission

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

See submission

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

See submission