**Feedback on the NDIS consultation paper – *Supporting you to make your own decisions.***

# Overview

The Client Consultative Committee (CCC) of CPL was started in 1993 in recognition that clients wanted a platform to advocate issues. The CCC provides engagement forums for clients to be able to speak about their issues and get involved in organisational decision making and planning. With a 30-year history, the CCC representatives continue to provide feedback to CPL executives and senior management on several internal and external issues including things like transport, housing, health, staff training, rostering, support needs and NDIS matters of concern. Ms Jennifer Johnston, current Acting Chair of the CCC, is submitting client feedback that has been captured with regards to the NDIS consultation paper – Supporting you to make your own decisions.

In 2020 Cootharinga a large disability service provider in North Queensland, joined the CPL group. CCC, CPL and Cootharinga worked collaboratively to gather opinions from participants and parents relating to this consultation paper and with a focus for feedback on the questions of;

* Who are the best people to help you (or a person with a disability) to make a decision?
* What should they do to help with decision making?
* How can they get better at helping?

## Consultative Questions

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

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

I am currently the best person to make decisions on behalf of my child, however, that will change as he grows. I want my son to be supported to make his own decisions, as he understands his needs best. *Parent, Toowoomba* Response:

I talk with my support coordinator, my support workers and my service facilitator when I need to make a decision. *Participant, Brisbane*

Response:

I make my own decisions. I may talk to my sister, my Household Facilitator or Service Manager if I need to talk a decision through. *Participant, Brisbane* Response:

My mum Elizabeth. My sister Becky. My other family members to a degree. *Participant, Gold Coast* Response:

I do not know. The only help I have asked for has been an Occupational Therapist, but it has taken me 11 months to even be able to source one and then she was the most negative and unhelpful person I have ever dealt with. I was so depressed after her visit. *Participant, Rockhampton* Response:

I make most of my decisions on my own, but occasionally I need assistance from my power of attorney or other people like doctors, specialists or CPL managers. *Participant, Brisbane* Response:

My sister helps me make decisions. I tell her what I want, and she makes the decision with me. *Participant, Brisbane*

Response:

My daughter makes her own decisions. She has been to university and is good at thinking through situations. She will sometimes talk to the staff at her SIL or the manager if she is unsure about something. She will also talk to me. She may email me; we talk in person or on the phone about the decision she needs to make. *Parent, Rockhampton* Response:

Cheryl makes decisions about day to day things like what she wants to eat and where she wants to go on a given day. I make the other decisions for her. When a big decision needs to be made, I talk to my brother and sister-in-law to get their help with making the decision. *Participant Sibling, Brisbane* Response:

I speak to my Household Facilitator, and my informal decision makers. The Public Trustee helps me with my finances. *Participant, Brisbane* Response:

Myself and my service manager. *Participant, Cairns*

Response:

Parents and sometimes support workers as long as it's in the best interest of Steven. *Parent, Townsville* Response:

 Family. *Parent, Townsville* Response:

Main support workers, family and Therapists (OT & Physio). *Parent, Townsville* Response:

I make my own decisions. If I need to make a big decision, I talk with my support workers and friends to ask what they think. *Participant, Logan*

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

Response:

For people with a disability who have difficulty making decisions they would benefit from accessing a service that could help them. The service can talk to them about their options and provide information that is easy to understand. Support workers can provide help by assisting people to research and find out information from credible sources on the internet. This can assist them to make an informed decision. *Participant, Logan* Response:

Understand need vs want and appreciate that both are equally as important. *Parent, Toowoomba*

Response:

Support me in every decision I make. *Participant, Brisbane* Response:

Listen to me and respect my preferences. Be responsive to what I decide. *Participant, Brisbane* Response:

They should listen to me, understand me and my needs, and guide me the best possible way to live a full life. Not rushing me, taking time to work things out with me. *Participant, Gold Coast* Response:

Listen and care. *Participant, Rockhampton* Response:

To make a decision I may need information provided verbally and in pictures to help me know my options. *Participant, Brisbane* Response:

They should listen to me and take in consideration my needs and aspirations. To have the freedom to be involved in making those decisions and be consulted before any decision is made for me. *Participant, Brisbane* Response:

Talking through the pros and cons of different options and checking they are understanding what is being said. Helping people to access expert information when this is needed. Occasionally I find out my daughter has made a decision, but she may have not thought through all the consequences. When this happens, I talk to her about this to make sure she has considered all the implications but still respect her right to make the final decision. *Parent, Rockhampton* Response:

To help my sister make a decision she needs to be given two options to choose from. *Participant Sibling, Brisbane* Response:

Telling me pros & cons of the situation and explaining to me what their opinions are. *Participant, Brisbane*

Response:

Gather opinions from everyone involved to help parents help customer make informed decisions. *Parent, Townsville*

Response:

Provide advice when needed. *Participant, Cairns* Response:

Try to help and encourage Steven to make the right decisions. *Parent, Townsville* Response:

To include him more in decision making.” *Parent, Townsville*

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

Response:

People to listen and to involve me to make decisions. *Participant, Cairns* Response:

Support workers need training so they can understand their duty of care, what type of issues they can provide support with decision making and how best to do this. *Participant, Logan* Response:

A decision needs to be made collectively. My son does not currently understand the importance of having his needs met over what he wants. However, this will change as he matures and he will have a greater understanding for what is best for him, physically and emotionally. This needs to be acknowledged when making important decisions later in his life, that his capacity has grown. I cannot be the default decision maker for him through his adult life. *Parent, Toowoomba* Response:

Listening more about what I want. *Participant, Brisbane* Response:

Have some empathy and at least try to help. *Participant, Rockhampton* Response:

Support staff need to be motivated and support people to look at their options. *Parent, Rockhampton* Response:

Her support staff are pretty good at supporting my sister to make a decision. *Participant Sibling, Brisbane* Response:

Work with me towards my own needs and interests. Explain to me why and how some of the decisions a made, so I will be able to understand it better. *Participant, Brisbane*

Response:

My preference is to have face to face meetings/ phone call conversations when I need to make a decision. *Participant, Brisbane* Response:

Sharing information and staying up to date. *Parent, Townsville* Response:

By socializing with Steven and having access to information/knowledge for Steven to make decisions. *Parent, Townsville*

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.

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

1. **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?**

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.**

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

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

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

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

Response:

My sister has a low IQ and not much life experience. We do try and give her opportunities to make decisions about things that affect her day to day life, but I don't think she will ever have the ability to make decisions about bigger issues. *Participant Sibling, Brisbane*

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

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

Response:

Some people with a disability have an adult guardian appointed to make decisions for them. Often there can be delays in them making decisions. I think this process needs to be improved. *Participant, Logan*