

Peer advice for people with psychosocial disability applying for the NDIS





The following resource was developed from a research project on Choices and Choicemaking in relation to the NDIS. The set of suggested guides come directly from people with psychosocial disability in the three major trial sites who have NDIS plans and funding packages. The advice aims to share some of the experiences of those interviewed and what we learned.

Strong themes from feedback are to be well-prepared, persistent and have a reliable and trusted person for support.

Applying to the NDIS

Step 1: Make an application to see if you are eligible

Strategies to help with the application process

• Have a trusted person make first contact with the NDIS



Look for information or apply online

My actual counsellor said about this thing, about the NDIS coming up and I thought, there is no way, with my issues, I'm not going to actually tick the boxes, so I actually went online and did a questionnaire and it said, yes, I could, so, that's how I got into [NDIS]. (Ali)

 Talk to other consumers and get information. These consumers are people who have already accessed a plan with the NDIS

[My son] went the first day it [NDIS] opened in Newcastle and spoke to them. And they said, "Oh yes, your mother's exactly the sort of person that we would help". (Alex) • Have a trusted person help fill out the forms. Get the support of a friend, family member, support or peer worker, case manager, or existing service provider

Well, the best thing I did was actually come in here [service agency], and this is where they done all my paperwork and all of that for the funding and that, so I could get the funding. (Lou) • Have a trusted person help write down your needs and goals

[My support worker] was with me for two hours asking all the right questions and pretty much wrote this amazing three-page thing out to say, this is what she needs. (Rory)



Step 2: Organise your evidence of disability, including assessments



Strategies

• Be prepared to follow up to get assessments and documents

A report from your psychiatrist will also be very helpful.

Step 3: Follow up



Strategies

• Follow up if you hear nothing

So I went and applied ... Didn't hear from them for 14 months ... if I hadn't re-contacted them I probably never would've heard from them (Parker)

 Be prepared to apply again – be persistent

Preparing for the NDIS planning session (pre-planning)

Step 1: Find out if you can have your choice of planner



• Ask your service provider or peers if they know how you can choose your own planner

I didn't get any choice over the planner though I think if I'd gone

a different route I would have, because I know through [various] organisations they have individual planners, so I guess if I'd gone to the support organisation first, I would have been choosing a planner. (Quinn)

Step 2: Decide on planning format and venue that you want (face to face, phone)



- Remember you are allowed to choose the mode of planning session you prefer
- You can decide on the venue for the planning session

I told them I didn't want it at my house. (Remi)

Confirm the venue



Step 3: Decide whether to take someone for support



Strategies

 Decide if you want to take someone with you and who is the best person: People have taken peer workers, support workers, family members, or an advocate whether they be formal advocates (support services) or friends

It's a good thing [to have an advocate attend] because sometimes I forget about a few things, and they might bring something up and I say, "Oh that's right, I did that but I didn't know it at the time". (Lou)

Step 4: Become familiar with the NDIS and its terminology



Strategies

• Find out what you can ask for and what can get funded

I don't know what to ask for. I don't know what's available and – I don't know. (Remi)

• Find out what the words they use mean, like 'core' and 'capacity building'

See, I didn't know what 'core' was. They don't explain to you what things are. (Ali)

- Be prepared for the NIDS to frame the "what you want" in goals terminology
- Make a list of questions you need answered by the NDIA

If I had my time over again I would've gone with a list of questions. (Rowan)

Step 5: Think about what you need and want

Strategies

• Think about your history, your needs and goals

But then I had to work out my next step, what I wanted, for me, what I want to do, because I don't know what I want. (Ali)

 Think about what supports you need to prevent you from becoming unwell, while you are unwell, or after you are unwell

If I've got the right support I won't have that fear of coming out of hospital, because I fear it now. (Ellis)

 Get help from someone you like and trust to think about what you want



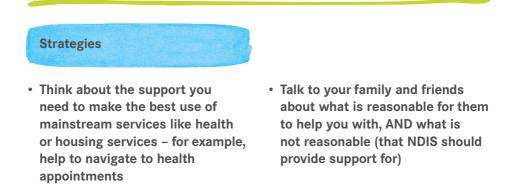
Write down a draft plan or a wish list

When I was going for my first interview with my local coordinator, I wrote my wish list down of what I would like ... I put them ordered. So, cleaner fortnightly, episodic care when discharged from hospital, because when you get out of hospital you're still not right, you're still crazy. (Ellis)



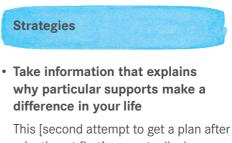
• Expand your thinking

[Develop] a greater awareness of what you can have [in an NDIS plan]. What difference it can make to your life. I don't think there's any sense of that and I've got very dull ... requests ... goals. (Lou) Step 6: Identify the supports you already have in place including those that are funded from other parts of the system (e.g. through the health area) or those that don't get funding



Step 7: Organise the documents to support your needs, and the services and supports you want





I his [second attempt to get a plan after rejection at first] was actually done with a lot more supporting material. My brother wrote a letter, my sister-in-law wrote a letter, my mother wrote a letter, my doctor, GP, psychiatrist and everybody else, psychologist, were all involved. So, there was much more support for me. (Marley)

The NDIS Planning meeting

Strategies to help with the planning process

- Explain how your mental illness affects your life (everyone is different)
- Keep a record of who was there and what was said, to help you follow up later

Get a contact name, email address and phone number.

• Choose to develop a plan for a one year or a two-year period

You can have it in one or two years. And I've come to two so I didn't have to worry about losing funding, as a lot of people are losing funding on the second time around. And I thought, well, I'll go for two years and challenge it if I need to. (Remi) Explain your needs and goals

 get the planner to listen and understand

... my planner was actually very good. She was very kind and very understanding and when I said I had a household management issue, she understood exactly what that meant. (Marley)

- Be prepared to be assertive even when you don't feel like it
- Take someone to support you

I would advise everyone to go with someone. An advocate, someone who will speak up when you're being railroaded [for example, take a good support worker] ... My point is that you just have to go in with someone who knows as much as possible, rather than go in there raw. It's the only way. (Remi)



• Take evidence to support what you want

I gave them a letter in terms of why it was important to me and then I gave them a whole lot of research in terms of how that research, the types of services supported people with bipolar or with PTSD. But they wanted specifically a report from my psychiatrist and my psychologist. So I got one of those from each of them supporting the service and what I was doing, but from different perspectives, related to me. (Quinn)

• Explain how you want your money managed

I was able to self-manage all of my money, with ... [support worker's] help, because I wouldn't want to do it alone. (Alex)

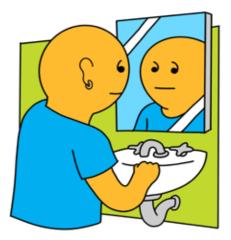


• Be ready to have follow-up conversations with the planner to finalise the plan

Seek assistance from family or friends if you need help in this area.

Be prepared for a less-than-perfect process that could take an emotional toll

My very first planner listened very well. But I found the interview incredibly traumatic. I just cried for hours after it. But since then it's been all right, in terms of interviews. (Remi)



What to do once your funding has been approved

Strategies

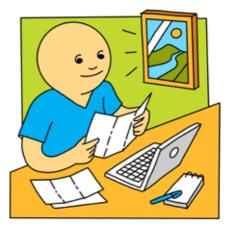
- Look out for your plan in the mail and keep it in a safe place
- Keep the plan / funding information in a safe place you can find



 Get information about services to help you choose which ones you want to use I met with, I think it was three representatives from three organisations and made a choice to not go with two of them. I'd heard some negative feedback about one of the others and I made a choice on that basis not to go with them. And so far, so good. (WA 8)

Identify the things you need in a service and the characteristics of a good service for you

[My] support coordinator... said, "There's this organisation, I think they're great. Why don't we meet with them?" I was happy. The explanation that I was given about how that organisation worked, their philosophy, I thought that's really good, so I didn't look any further. (Ray)



Using your funding for services and supports

Strategies

 Get ready to deal with a plan that doesn't give you what you have asked for

They want me to have [support person] twice a week but I'm sort of putting off until I can think in my own head what's going on here. (Lou)

Work out how to use your plan and do the budgeting and manage the money with help where needed

[My support coordinator] comes around to Mum's house, and I go to Mum's house and then we sit down and have a planning meeting and she tells me what I got and I don't have ... I'm happy that it's managed by somebody else because it's too much information for my brain to handle and I get confused. (Morgan)



- Learn to use the NDIS portal
- Call the NDIS to get your access code

The only way you can do it is go into MyGov. The last time I saw my support coordinator we looked it up, and nobody had been taking any money at all other than the lawnmower bloke and the psychologist. (Finley)

Not just MyGov, it's actually the NDIS's portal as well ... Once you get in there are issues to do with being able to access financial details and things. It's been down a lot of the time too I think. (Marley)

Because we can now go into NDIS online and we've got portals, we can go into there and I can just have a look, but I've got no idea what's what. (Ali)

That portal, the NDIS portal, that's hard to get on, and I'm tech savvy ... You log in to your details and it's like, go to this bit, but then you have to click on this link, and this link. (Morgan) Many people don't use the portal, and that's ok. If you have a plan manager, they can keep track of money spent." Ideally people will use the portal eventually, but it's a lot to get your head around at the start, and some people don't have access to the technology and that's ok.

Keep using services and access funding outside of the NDIS (e.g. mental health plan, diabetes plan etc.)

I do have an Exercise Physiologist, but I got that through my ... Diabetic Heath Plan... So, I've already got funding for it, sort of thing. (Remi)



• Recruit the staff you want to work with you

When I chose Suzie [support worker] ... she came with her boss for an interview, for me to check her out. (Remi)



• Develop your self-confidence - it's okay to give staff instructions and feedback

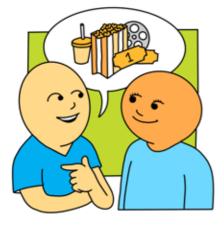
But with ... individual support, you can actually [say to the support worker] ... I want to go see a movie or go do the cleaning. (Morgan)

Make sure you have the right support coordinator – it's okay to change

You have to get the right Coordinator of Support officer, someone with experience. But my Coordinator of Supports has been absolutely fantastic. He meets with me fairly regularly ... he listens ... he has suggestions, but doesn't force it on you. (Remi)

Make complaints about service provision

Well, I suppose, I could have a choice [of support worker] if I put in a complaint. And I tell you what, I've had to complain three times ... and I've learnt heaps by that ... I've had to complain that I wasn't getting the support that I was supposed to get. (Remi)

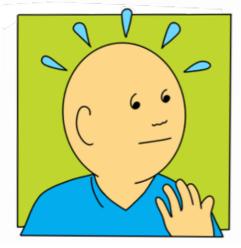


Review of plan (after 12 months or 2 years)

Strategies

• Seek an early review to address changed circumstances

They shouldn't leave us hanging all the time, waiting for a review which never comes. (Marley)



- Organise someone to come to the review as a supporter
- If you have a support coordinator they will help you prepare and support you through the process then attend with you if you choose.

And, {my support worker} could also come with me into the NDIS review ... So, that makes me feel good, because I've got her there, and if I forget something, she can remind me ... that will make me feel supported, and less likely to have forgotten something important. (Blake)

• Manage the fear of losing funding on review

I'm so concerned about my review because these things that are starting to be put in place. (Hunter 3)

I panic a bit because it's like, okay, my plan finishes on this time. I wasn't quite sure that if I don't get a meeting, does it stop? Do we have to redo it all? You don't want to do that again. (Ali)

 Reflect on past services and identify what services and supports are needed for the next period

Yeah, [I have a sense of choices this time around] because I spoke to a few people, what I can and can't have and what I have, but - and I know what I want ... so I can sit there and say, can I have, or, I'd like this, or whatever. (Ali) • Deal with negative outcomes if there are any

That woman that I spoke to for the first review – she told me the review had been done and they weren't giving me any more funding. She was quite rude about what my needs were and also condescending. (Spencer) With information, preparation, support and follow up, you can get the support and services you need from NDIS to help you reach your goals.



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