

Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT

I am a carer, or as I prefer, a support person for my son who has a psychosocial disability, having a chronic, severe ongoing mental illness and complex needs.

As a carer of someone with a psychosocial disability, I have been a strong advocate for the inclusion of people with a psychosocial disability in NDIS and for their complex needs to be understood by NDIA.

I have been involved nationally and locally in many different forums on the NDIS from its inception, so it came as a shock to me that I was overwhelmed and anxious going through the process. I put this down to our experiences of the mental health system for over 12 years. We had learnt not to trust and to be cynical.

The NDIS was our last hope, so we began the process in trepidation several months before our son was eligible to access it. We knew that it could take a long time for him to trust and engage mainly due to the symptoms of his illness, medications and past experiences.

At this time my son was at a Mental Health rehabilitation facility and the application forms for eligibility to NDIS were sent there. This was an advantage as the psychiatrist was able to complete his part of the form without us having to chase him up. He also knew our son very well as he saw him every week, that is, not just for a half hour consultation every three months.

The application form was hardcopy and this actually became a stumbling block for us. Here we were in the 21st century, used to completing forms electronically, but being asked to provide hand written information in restricted size boxes, not being able to type, think, edit, or fit all the information in the allocated boxes in legible writing, running the very real risk that the NDIA would be unable to decipher and assess his eligibility to the scheme. We contacted NDIA for an electronic version but were told “they did not do that”. Being resourceful I managed to obtain an electronic version from a Mental Health NGO ... so they do actually have electronic versions. As my son does not “do paperwork” we completed the form and provided

all other reports and information that would assist the NDIA in making an informed assessment.

During the pre-planning stage, my husband and I attended a carers' information day specifically aimed at carers of someone with psychosocial disability. We were also given information, such as how to do a carer statement and the Mental Health Australia's Mental Health Carer Checklist guide.

We completed the Mental Health Carer Checklist guide and provided a Carer statement along with our other documents to NDIA. The checklist is a very important document for the Carer to complete and give to NDIA, as it will give a full picture of what you as the support person provide and what impact this has on you and your family.

The crucial part of our pre-planning preparation was to use MiFellowhip's (now Well Ways) "Your Voice Your Choice" project. The consumer peer worker employed in the project gained our son's trust, and over several meetings over several months managed to engage with our son to ascertain some goals and aspirations he had. The peer worker also met with my husband and I for our input as to what support services were required for our son to live more independently, and achieve his goals. He then met with my son to get his approval of the additional supports my husband and I had suggested. I worked with a carer peer worker during times when I was overwhelmed. The staff involved in our son's rehabilitation also contributed to the plan, to build on the work they were doing for his recovery. The final version of the plan was approved by everyone, and then presented to the NDIA mental health planner. It is very important to get a planner with a mental health background who understands psychosocial disability.

Finally all involved in our son's care, as well as our son, met with the NDIA mental health planner with the proposed plan and the Mental Health Carer Checklist. The mental health planner approved of the majority of our plan. The provision of a support person to stay overnight in the event of our son becoming unwell and would prevent a crisis team visit, hospital emergency, or admission into the adult mental health unit, was not approved as the NDIA did not allow overnight stays in a one bedroom home. The plan was taken back to the NDIA assessors for approval and we were successful in having our son's plan approved.

In our plan we did not opt to self manage and asked for provision for a Support Co-ordinator for several reasons:

1. We did not want to self manage as this would mean that my husband and I would be managing the plan and this apart from anything else was not sustainable – we ourselves could become incapacitated or to put it bluntly die. We are no spring chickens.
2. Self-managing especially if it is a parent and child relationship could create tensions between the consumer and the carers/support person and potentially ruin relationships.
3. If things go wrong while engaging or employing service providers especially if they are not registered with NDIA then it is problematic and can cause a great deal of stress, anguish and financial issues.
4. We do not have to deal directly with the NDIA which has proved to be very problematic, time consuming and stressful.

The mobility allowance component of his plan however is self managed and that goes into my son's bank account. Our son is with the Public Trustee but the Public Trustee will not manage NDIA funds so my son manages this part himself and uses the money to buy bus passes, taxi fares if needed and to pay a support worker to take him to appointments if needed.

At this point I will also emphasize that after beginning this process, we managed to obtain a housing transfer for our son to a small town house in a safe, secure environment in amongst good neighbours, and this also made a huge difference for my son's recovery, and importantly for the implementation of his NDIS plan.

We chose a Service Provider who also provided the Support Co-ordinator (and we much prefer to have our mental health Support Co-ordinator rather than having an LAC that has no knowledge of psychosocial disability and does not actually co-ordinate supports and services). If we did not have a support coordinator I would be doing that role. We now work very closely together, our son, my husband and I, our son's Community Mental Health clinical case manager and our Support Co-ordinator. We work well together and make a good team. We also have regular interaction with the support workers, other services providers, and the housing manager who attends relevant meetings.

We have never had so much relevant on-going support. There were glitches such as the domestic cleaner service provider de-registering from the NDIA forcing its customers to self manage or go elsewhere, though as it happened we were not too happy with their service anyway so were able to employ another service. There were also some problems with NDIA not paying service providers on time. NDIA's computer system was very problematic, and still is though I understand that this is going to be rectified. Our son's NDIS package was making such an enormous difference to our son's life and ours.

We were no longer a charity case being grateful for whatever crumbs were thrown at us, we now had ongoing, relevant and flexible support that we had control over.

Being considered a "success story" I became involved in promoting NDIS, presenting and advising other carers going through the process in many forums including webinars and being filmed for the Imagine More project, Carers Australia and Mental Health Australia.

Implementing the first year of the plan was a big learning curve and we were finding our way, working collaboratively with all involved in our sons care, ironing out issues, finding appropriate services, and discovering what other supports etc our son needed. We also needed to think longer term to anticipate how successive years plans would need to evolve to help our son achieve his goals and aspirations.

Being in the ACT our first plan was obtained in a trial site. Service providers and consumers and carers were learning what was working and what wasn't. This knowledge and our first year experience were helpful in preparing for our annual plan review. This preparation involved our support coordinator, clinical manager, support workers, my husband, myself and of course our son. We were all saying the same thing, namely to continue with current support plus a few additional things such as a plan manager so that we could employ people who were not registered with NDIA.

At our annual review we met with a planner who did not have a mental health background (and we suspect was from Feros), even though we had asked for a planner with this qualification. Our son was actually unwell during the interview but the planner did not notice this and would not have recognized that he was unwell. The planner said that you will not be penalized for moneys not spent. He also told

us that NDIA do not give funding for a mind dog, companion dog or therapy dog they only provide funding for blind or hearing impaired disabilities. (I discovered after doing some research that La Trobe University did research for NDIA into the benefits of a mind dog and their conclusion was that there was not enough research out there to accurately assess if the benefits outweigh the economic outcome.) This is despite that fact that appropriately trained dogs assist those with psychosocial disability, social anxiety, PTSD that have these dogs greatly benefits their mental and physical health and well being.)

We asked for a mind dog that was appropriately trained to assist him to get through a psychotic episode till he went to sleep negating the need to call the crisis team or have an admission to the Adult Mental Health Unit. The dog would also be able to remind him to take his medications at certain times and would be able to call for help if something happened to our son such as heart attack or losing consciousness, that would help him with his social anxiety and would be his “family” and companion. A dog would also help with his health and fitness as well as his overall health and well-being.

After the review plan meeting we all found it very hard to gauge how the meeting went, and our support co-ordinator who had been to many meetings said that every meeting was different and they gave you no idea of what the outcome would be. There is no transparency or consistency. We were however, quietly confident that we would continue with current supports, with the addition of a plan manager to employ the other services we needed.

Then the new plan arrived with no covering letter, no explanation, rhyme or reason of why my son’s plan had a reduction of funding to less than one quarter of the initial year’s plan. We were shattered to the core, absolutely devastated to say the least. We were also too frightened to tell our son, knowing that this would have a huge adverse impact on him and the progress he had made. The consequences of this were terrifying - the new plan’s inadequacies were potentially life threatening.

How were we going to pay for current services and support, let alone any additions? In addition, and somewhat absurdly, NDIA had granted a plan manager to employ other services! My advocacy work was now a very cruel ironic joke.

This process highlighted that the NDIA seem to have very little understanding of psychosocial disability. What damage were they inflicting on people with psychosocial disability and their carers/families, giving them funding, hope and a better quality of life one year and taking it away the next. This reinforces what has continually happened to them in the past.

We immediately put in a plan review request, engaged the Carers ACT Advocate, had on going negotiations we clawed back a lot of the funding to produce a viable package to continue with current support services, along with a plan manager to manage the plan. This was not completely satisfactory, but at least an improvement. However, with further negotiations, corrections of errors and also with service providers negotiating for all of their clients who had had their review plans slashed we received additional plans with better funding. I also received an apology from two senior NDIA people, one new to Canberra and the other in a Senior position outside Canberra which I was very appreciative of knowing that they understood and acknowledged the distress that this had caused my husband and I.

Subsequent to this our Plan Manager discovered a data entry error that meant that an amount allocated which was in thousands had had the decimal point removed and the figure was now in the hundreds. This clerical error could not be rectified without going through another plan review that by this time we did not want to do again, we had been through enough. This mistake however contributed to the fact that one our son's key workers had trouble getting paid and had to end up deregistering from NDIA so that we could pay him directly from the plan via the Plan Manager and even then it took 5 months for him to be paid. We were very lucky our service providers were dedicated and carried on providing services and support throughout the whole debacle.

We are hopeful that NDIA are starting to listen and to change some of their practices that seem to have evolved with the national roll out. The NDIA's computer system and incompetence has caused a lot of unnecessary problems and a great deal of distress not to mention the amount of money wasted on the extra work generated by these problems.

What we learned: the planner:

1. was not trained properly;
2. no mental health background/little understanding of psychosocial

disability

3. compulsory questions were physical disability related
4. didn't read the records,
5. didn't review the last plan to see what had worked, revisit goals, etc.
6. didn't compare amounts or he would have realized we could not pay our current services never mind for a plan manager that was granted;
7. different assessment tool used from original plan?;
8. computer generated assessment? Manual input?
9. unspent funding was used as a base line for the new plan, resulting in punishment for not using all funding. Planner does not ask why all funding not used. NDIA states that participants are not to be penalized for not using funding.

There are many reasons why funding is not spent especially in a first plan of a brand new scheme. We didn't use all the funding due to support from the Brian Hennessey Centre's outreach program for 6 months, a service provider de registering from NDIA, still adjusting to having funding, choice and control and discovering what services and supports were needed.

10. "reasonable and necessary" is assessed according to what is stipulated by NDIA and is not assessed on what is "reasonable and necessary" for the participant. This does not allow for more innovative solutions outside of what is set down as "reasonable and necessary" (eg companion/therapy/mind dog not funded for psychosocial disability even if reasoning is sound.);

I asked NDIA to clarify why they do not pay for the higher quality Peer Support/Recovery focused service at the appropriate level i.e. "life transition planning, mentoring, peer support and individual skill development" (Price guide Reference 09_006_0106_6_3)?

The line item the NDIA reference as "Capacity Building", developing individual skills and providing training (15_037_0117_1_3) is paid at less than Core supports.

Our support workers are qualified peers support workers qualified in recovery focused practices for capacity building which assists our son to lead a more independent quality of life with appropriate support that does capacity building with him and not for him which creates dependency.

I did not receive a response.

These practices undermine the whole concept of NDIS.

There is also a shortage of independent (of government) advocates for consumers and carers and it would be ideal if the support coordinator was given more authority to also advocate for consumers. This would relieve the carer of this onerous stressful role, would provide an advocate for consumers with no one to support and advocate for them and it would be someone that knows the consumer very well and has their best interests at heart. In the case of a possible conflict of interest accountability would be written into the service agreement. Currently the NDIA (or Feros) staff member has all the power and limited knowledge of the person and their disability and are not all trained properly with the relevant skills for such a responsible position.

Having an NDIS plan that is appropriately funded is making an enormous difference to our son's life, and therefore to ours as well. Although our son has been progressing well and has been achieving some good outcomes, the episodic nature of his illness means that progress fluctuates depending on how well he is. When he is too unwell then he is unable to use some of the funding in his plan such training for a job. He will always need support and services to maintain and improve on these outcomes and on his overall quality of life to be able to aspire to lead the life that he would like to.

The culture within NDIA places it in grave danger of becoming another Centrelink. In fact it is in many ways worse than Centrelink, at least you go in to Centrelink and speak to a person. You are unable to do this with NDIA, and if you phone you will be lucky to be answered and the person that you end up speaking to will be in Adelaide or Brisbane or somewhere else in Australia. There is an attitude forming that NDIS is welfare and this produces a culture that is judgmental and punitive. We are very worried and frightened of going through our sons next plan review, we do not want to have any further trauma or anxiety in our lives or have to deal with the fall out of any funding cuts in our sons plan. Having to fight again for his funding is something we do not want to contemplate, we cannot continue to do this for the rest of our lives. Most importantly: we shouldn't have to fight!

This is the biggest social reform of our time, and it has so much potential, we have to get this right. The rest of the world is watching and if we make it a success then it will have benefits for all of those people with disabilities.

The NDIS is in fact an investment just as education is an investment (perhaps it should be renamed the National Disability *Investment* Scheme). This investment is long-term, giving people with disabilities their human rights and making Australia a better place to live, both as an inclusive, equal society while stimulating long-term economic returns. The NDIS is creating a growth service industry providing “jobs and growth” and long term economic benefits for the whole of Australia.