



Women With Disabilities ACT
WWDACT

Women's Experiences with the National Disability Insurance Agency in the ACT

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Project Officer: Jocelyn Perry

strong women, strong voices

wwdact@wchm.org.au [02] 6290 2166 PO Box 385 Mawson ACT 2607
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www.wchm.org.au/WWDACT/wwdact



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Introduction:

WWDACT is a systemic advocacy and peer support organisation run by women with disabilities for women with disabilities. Established in 1995, WWDACT uses a human rights philosophy, based on the UN Convention on the Rights of Persons with Disabilities (CRPD). WWDACT's work is also informed by reference to the UN Convention on the Elimination of (all forms of) Discrimination Against Women (CEDAW). WWDACT works to minimise the effects of intersection of gender and disability discrimination and works with government and non-government organisations to improve the status and lives of women with disabilities in the ACT and surrounding region.

WWDACT, through its membership has strong links to relevant ACT advocacy organisations such as Advocacy for Inclusion (AFI), People with Disabilities Australia (PWDACT) and the Health Care Consumers Association of the ACT (HCCA). WWDACT also has a close association with Women With Disabilities Australia (WWDA), the peak organisation for women with all types of disabilities in Australia.

WWDACT is governed by a volunteer Steering Committee derived from its membership and its work is managed on a day-to-day bases by the Convenor and two part-time staff. WWDACT is auspiced by the Women's Centre for Health Matters (WCHM), with its staff employed as part of the WCHM staff team.

Background:

In July 2014, the National Disability Insurance Agency (NDIA) [the Agency] opened its doors to the Canberra public charged with the responsibility of introducing the Australian Capital Territory trial of the ambitious and exciting new National Disability Insurance Scheme (NDIS) [the Scheme]. The nationwide scheme, being implemented at a number of trial sites around the country was highly anticipated; promising a complete makeover of current disability services so that all eligible people living with a disability could be better off under the NDIS.

As people eligible for the NDIS and service providers began registering with the Agency, and individuals began to transition to the Scheme there was obviously going to be rapid and major changes to both the sector and individual lives. At this time, WWDACT began hearing anecdotal stories from women and service providers about their experiences with the NDIA's initial activity.

On March 27th, 2015 an article appeared in the Canberra Times, "*Bureaucratic 'gobbledygook' fuels National Disability Insurance Scheme*". (APPENDIX A) The article briefly outlined many of the matters voiced at a public hearing before the Joint Parliamentary Committee on the NDIS¹. Most of the issues raised were directly related to the implementation of the NDIS by the NDIA rather than the

¹ The Joint Parliamentary Committee on the National Disability Insurance Scheme was established on 2 December 2013, and reports to Parliament after 30 June annually on its investigations and findings in relation to implementation of the NDIS. Information is available at: http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/Role_of_the_Committee (retrieved July 19th 2015).

scheme itself. This was a catalyst for WWDACT to begin an exploratory research study with women with a disability who had engaged with the NDIA and hear their experience first-hand.

The information provided by the women will be used as a platform to guide further research in this area as the NDIS expands and matures. It will also be fed back to the NDIA to inform their practices and understanding of the lived experiences of women.

“Over time, we will find new and better ways of providing support, by building on what works well and learning from the lived experience of people with disability”².

Aim:

The aim of this study is to gain an initial insight into the interactions between women with disabilities and the National Disability Insurance Agency in the ACT.

Methodology:

This was a small exploratory study to hear the voices of women with disabilities in the ACT who have been in contact with the NDIA during its trial in the ACT. WWDACT’s priority group are women who live in the ACT, who have a disability, are over the age of 18 and likely to be eligible to become Participants in the NDIS. At the time of the study, the number of women eligible to enter the Scheme and who were within WWDACT’s priority group was small. This limited the number of participants who would partake in this research. Therefore a high quality information sample was focused on rather than one of sample size.

Women with a disability would be welcome in any role to take part in the study; whether acting as support people, family, friends, NDIS Participants or in a combination of roles. The simple criterion was that they had engaged with the NDIA. At the time the study was conducted, Participants in the NDIS in the ACT would likely include women born between 1949 and 1954 (the 60 to 65 age group), some residents of group homes and some school leavers, because the ACT phasing schedule included people in these groups as the first intake to the Scheme.

Initially the researcher conducted five informant interviews with a range of ACT organisations involved in the disability sector. The purpose of these interviews was to hear the informants’ ideas on the key issues around the NDIA in the ACT and gain background information for the researcher. The information provided by the informants was to help shape interview questions for research participants. However in reality this input was limited.

Flyers and information were sent out through various networks and organisations promoting the research and seeking participation from women. Six women responded and agreed to participate in a semi-structured interview. Two days before the report was completed one woman contacted WWDACT wanting to contribute. As there was no time for an interview she wrote a lengthy email

² <http://www.ndis.gov.au/what-is-the-ndis> (retrieved June 25th 2015)

outlining her experiences. This information has been summarised and included at the end of the results section.

Interviews with women were conducted in a location suitable to them and without timeframes. One interview was conducted and recorded via speaker phone. Women were encouraged to tell their story and the things that were important to them. The interviewer had a list of questions (APPENDIX B) which were used as a flexible guide only. Women led the conversation and questions were dependant as to the particular women's journey. The majority of questions were focused on their experience in interacting with the NDIA rather than on details of the NDIS itself.

The opportunity to contact the researcher post interview with further information was offered to the participants. Three women did this via email and telephone and this data has been included in the results with their permission.

The women's interviews were part-transcribed by the researcher to extract information about key points, with recordings kept on file for complete transcription to be outsourced to an independent transcribing service in the future. Extracts from the interviews have been presented below in vignettes to provide insight into the journey these women have had with the NDIA; to present their individual key experiences and sentiments as told by them.

The transcripts were also coded and thematically analysed. Key themes were identified in the data and have been briefly discussed in the "Insights" section of this paper. This section has been purposefully restricted due to the limitations discussed below. It is the researcher's hope that the women's voices, as represented in the vignettes, speak for themselves.

Limitations:

Caution should be used in making broad conclusions or generalisations from this report as the sample size is very small. Women were asked to participate regardless of the role in which they interacted with the NDIA or how much interaction they had with the NDIA. The context of each woman's engagement must be considered when interpreting their experiences.

The vignettes and discussion can only provide insights into the lived experiences of the individual women and highlight potential learning opportunities and areas of interest.

Results:

The seven women who participated in the research were all at various stages of engagement with the NDIA and their interactions had been in a variety of roles. Their names and family members' names have been changed for privacy reasons. A summary of the journey they shared has been provided below. Direct quotes from the women are in italics.

Grace

Grace is an enthusiastic supporter of the NDIS. She is genuinely overwhelmed at its potential to transform people's lives and is passionate about sharing this message with others. She has witnessed the benefits first hand in driving the development and implementation of her son's (Peter's) Plan. She is currently going through the same process for herself. She is honest that this journey has not been without hugely stressful episodes, however, so far these have been outweighed by the positives.

Initially, Grace reported that she had received a letter from one of Peter's primary service providers. It outlined that he would be transitioning onto the NDIS. At that point, Grace started going to information forums provided by the NDIA or the ACT Government. She found these useful but was worried about how others were coping with the information given and the changes that would be made.

"I found myself speaking quite a few times (at the forum) to help other people which was really interesting. I found that some people were very... we're finding it hard to change. You know how we like choice and control, because they were sitting in this mould for so long, they were very, some were actually fearful of the NDIA and NDIS"

Grace got in touch with an advocacy organisation to discuss the process of Peter entering the NDIS and ended up working closely with Peter, an advocate (Annie) and an NDIA planner (Christine) to develop Peter's Plan, and then to commence its implementation.

Peter's planning got off to a shaky start. Grace was really upset by how the process was evolving and felt Christine didn't understand the situation. However with time, a positive and productive relationship evolved.

"She was terrible at the beginning because she wasn't listening. Because I said I wanted him out of the group home, where he had been beaten up so severely and like she wasn't listening and I ended up walking out of my house to try and keep calm and Annie ended up having to advocate."

"I would say (Christine was) the worst in the beginning and the best at the end, and I was so proud of her because she helped me with so much and did such a wonderful job."

"It was very difficult at first but in the end it was wonderful. But at the beginning, she'll (Christine) probably laugh at me for saying this but she'd probably agree and so would Annie, it was terrible because she hadn't had...experience with anyone like Peter before."

Annie negotiated for Peter to have some extra functionality assessments. The reports from these provided the evidence which enabled a significant difference to the supports incorporated in his Plan. Other major changes, such as leaving his Group House accommodation were included. Grace has been careful not to make too many changes in Peter's service provision too quickly and staggered the implementation of some parts of the Plan.

"and I'm also keeping some of the old, so it's not too unfamiliar, so it's not too hard"

Transport was an area of concern which needed some creative planning.

"now that's (transport) all sorting out but that's another concern that there's not enough finances for people's transport like Peter...a lot of Peter's plan is 'flexible supports' so a lot of it, often you'll be dipping to another support which will cover that"

Grace has thorough knowledge of the ways in which Peter communicates and was able to integrate his needs and wants into the Plan. He was involved in making as many decisions as possible, pointing to activities he would like to do more, or which made him feel good. Involving individuals in their own planning is something Grace feels particularly strongly about and thinks it is an area in which the NDIA could greatly improve. This includes presenting the Plans in a format that is compatible with participants' communication strengths.

"I've even had highly intelligent people with top secretarial skills who can't read this (Peter's Plan) or comprehend it and we're dealing with people who have got profound and permanent disability and we need to meet the individual one on one. Maybe for example a pictorial, if they can't read and they only live by, for example pictorials, how are they going to read their Plan? They can't."

"We've tried to have a talk but some of it, I think was a bit over his head and I think I'm still looking for how's there a way better that I can help my son understand their Plan?"

Implementing Peter's Plan has had its highs and lows. Annie continues to advocate and support Grace and Peter through this process.

The initial changes saw an incredible change in Peter.

"He's already smiling and he doesn't normally smile, and he's just so much happier already at the change that's been happening."

Due to some changes in Peter's therapies, he is *"excelling in amazing ways, doing things he could never do in whole life"*. His functioning is improving continuously.

Grace firmly believes that *"Peter's plan, when it was finished, is the best thing that's ever happened in his whole life"*.

The service provider Grace chose to coordinate Peter's Plan has caused considerable strain and anxiety for both Grace and Peter. Peter began self-harming and Grace felt she was not being listened to and was angry at the way Peter was being treated. This caused high levels of stress for Grace who ended up seeking support from a psychologist. She aims to change service providers to suit their family's philosophy and requirements.

Grace is now in the midst of developing her own Plan. Annie is her advocate and Christine her planner. This continuation of relationships has been important as they understand the family's aspirations and realities. She has jotted down ideas and hopes for to get her Plan approved over the coming months. Improving literacy skills, finishing a Certificate IV, parenting assistance and other professional development are all included.

"I'd like to have some parenting assistance because my son, in areas where I haven't been able to reach him in communication, because even though we have this amazing thing and I can do a lot for him, if I had some specialised training, parenting skills that would help me with my disability and to help me parenting with Peter, to help him have a better quality of life, then I am looking at those things in my plan too"

Part of the process will involve having medical assessments. Grace has experienced a transient lifestyle and as a result clear diagnoses have been overlooked.

"because it looked like I had a track record of instability when in fact I had a lot of disability issues no one had faced. So at the moment, at [age stated] years of age, I'm going to be undergoing a lot of assessments"

Grace is particularly interested in undertaking an assistive technology assessment.

"There is so much assistive technology in modern day that I can't do, my colleague says, in that area I am about 25-30 years behind"

"So many people in the community have said "How do you get onto this women's website? I haven't been able to do anything like that so it will be greatly beneficial to me and Peter, but to many people in the community as well, and it would also improve my life ability if I get the right help, right assessments and the right help, then they are going to need to help me less when maybe I am 10 years older"

As Grace continues developing her own Plan and irons out the implementation of Peter's, she is positive and confident about the future and their ability to make decisions to suit them.

"I don't want to self-manage, it would worry me... because I went through a lot of my life with some depression and anxiety issues and so I don't want that kind of stress over my life"

"And then there is always choice and control if there are ever any issues that need to change, then we're flexible"

"Most definitely the choice at the moment, the control, the choice of what my needs are in my life, which is all of what I haven't received in my life and probably my life would have been very different if I had of had that help, the NDIS as a young child, my whole life would have been totally different from the way it's become"

Grace is passionate about sharing her experiences with others and encouraging them to make contact with the NDIA and embrace the opportunity. She emphasises the essential role an advocate has played in her and Peter's journey and highly recommends others seek this assistance.

“Peter has got so much more due to Annie. I am always leading and Annie is just empowering what I write or say”

“Annie, she was just like a golden, I think she deserves a limousine, a promotion next to Tony Abbott or something!”

Grace concludes with a reflection upon her own interaction with the NDIA and advice for others who will engage in the future:

“I’ll speak out, I’ll rock the boat, that boat needs rocking! Don’t just dance with it, rock it, you will get a much higher quality of life for it!”

Paula

Paula has attended some forums and meetings where the NDIS has been discussed and also received information via email. She is engaged with community organisations such as her church, WWDACT and the Mental Health Community Coalition (MHCC). It is presumed from the conversation that her understanding of the NDIA and NDIS has come from a variety of community organisations and possibly the NDIA itself.

“they are always talking about the direction for the disability people, what going to achieve, what benefits, more education opportunities and policy development”

“NDIS can develop lots of policy and more education for the younger people”

When Paula was asked what this might mean to her as an individual, the potential significance of the NDIS to her life, she was not clear.

“no I don’t know, I don’t know that a little bit confuse me. It didn’t meet my needs, I couldn’t.”

Paula hasn’t visited the NDIA but knows where the Braddon office is.

“I saw the big building. I think that’s the main office, we not allowed to go there”

Paula said the NDIA can contact her if they would like and she wouldn’t mind meeting with them.

“I don’t mind, if they really like to see me”

If the NDIA contacted her, she thought she would get some support from her church group where she feels comfortable. She had previously been in touch with a local advocacy organisation but didn’t think they could assist her with the NDIA.

“I’ve been to that (advocacy organisation), they said they are only helping people who are, you know, severe disability, we are OK, I’m mobile and can move around”

Paula thought that if she could change the support she currently gets she would like to incorporate some assistance with her children, family and around their home particularly with gardening and repairs. Improved access to computers would also be really useful.

Diana

Diana has followed the development of the NDIS since its formulation stage. She is very well informed around all aspects of the scheme; its principles, stages of development and legislation. Diana has attended many information sessions and also read independently, not only out of personal interest but with the understanding that the NDIS was going to be important for a wide range of people.

“They (Imagine More³ workshops) weren't well pitched for me and I'd already done so much homework that I probably didn't need them. However I kept going to them for a while and to other events that the ACT government organised or sponsored or that the NDIA organised later. I kept on having the same experience where there was very little new in anything”

Diana had spent some time trying to get a clear answer on some specific aspects of her own situation. Her main queries were around eligibility criteria, the level of severity a disability needs to be to get accepted onto the scheme and conditions which are perceived as permanent for some individuals and not others.

“so essentially I'd ask questions and get back 'Yes Minister' responses. I would keep saying these questions and they'd come back and say [regarding the level of severity] “well if you need supports”. Well that can't possibly be the criteria because there are degrees of supports. And I know, I grew up on “Yes Minister” and “Alice in Wonderland” and I know and I've been a bureaucrat so I understand when you are getting the run around and I was getting the run around”

In June 2014, Diana was told that the forms would soon be available for her to apply for eligibility. Due to the nature of Diana's disabilities she knew she may not be eligible but had been advised by an NDIA staff member to apply and find out. She was concerned about supplying enough evidence to support her application and was informed by NDIA staff on many occasions that they could quickly get more information from specialists if needed. The forms arrived late. Although sceptical, Diana completed and lodged her form with supporting evidence from her GPs and some older specialist reports.

The NDIA contacted Diana's main GP for further clarification on Diana's disabilities, namely their permanency and evidence of severity. Diana was confused, as this information had been provided on the eligibility application, but not surprised. This possibility is why she had been questioning how to evidence her situation.

“my sense is, she (the GP) felt she was responsible for telling them what things they should accept, which is inappropriate. She is responsible for telling them what she considers are my conditions, their impact, but she doesn't have to make the judgement about what they should accept.”

Diana had requested that all further communication between the NDIA and herself be via email. Due to her disabilities this is her preferred method. Not long after she received a phone call to discuss

³ “Imagine More” is a Canberra based NGO, describing itself as a change agency advocacy group (<http://imaginemore.org.au/>). They have conducted a series of workshops for potential and existing NDIS Participants.

her application. Her request had not been passed on. This call was to discuss the rejection of her application; the reasons given seemed to be contradictory to the evidence Diana had provided.

“she clearly hadn’t read my application”

“She shouldn’t be ringing me about saying no, without being familiar with those documents”

The NDIA staff member agreed to consider further evidence from Diana’s GP. There was some to and froing with communication and mixed messages given from NDIA staff about the state of her application. Diana considers many breeches of verbal agreements were made. In the end, Diana’s application was rejected the day before the NDIA needed to make their decision.

“And my feeling was they were time planning very badly, a solution to not meeting the, what I recognise as, unreasonable timeframes due to the legislation. They are solving this by making unreasonable poorly thought out decisions [before the deadline].”

Diana appealed the decision as well as made a complaint.

“I also made a complaint because it seemed to me, what had gone wrong were processes and in order to get a fair decision the processes had to be fixed.”

She worked with ADACAS through this procedure and *“felt wonderfully supported”*.

“You know I had had these wonderful experiences (with advocacy organisations) but it never occurred to me that I would need them over this one. And so getting the word out about the benefits of having some advocacy way beyond this self-advocacy stuff would be good”

Diana was shocked to be told by an NDIA staff member that he was reviewing her appeal as well as the complaint. She thought this was completely inappropriate but didn’t want to “rock the boat” as the staff member was being respectful and helpful. The review officer agreed to allow her to provide evidence in any areas that he felt it was lacking, but did not do so. In the end Diana was accepted into the NDIS without providing further documentation and considered that the eligibility decision had excluded several of her conditions from being eligible. She was reassured that she did not need to make representations about this because during the planning they would look at the ‘whole person’. The planning was to be done through conversation which Diana had previously stated as unsuitable.

“So I had an agreement that I made with them that I would prepare the participants statement and then we would talk about it, we could go back and forwards”

Diana chose to undertake the initial planning process alone even though the form templates were somewhat frustrating and confusing.

“I just didn’t want her (the planner) producing a draft plan because my experience is that if someone else produces their document then they’re wedded to it. It’s harder...I am likely to get a better outcome if she has to say yes or no to my proposal than if she had to let go of hers”

The NDIA requested many documents from Diana which took time to locate. She found hard to see some documents' relevance, others brought up areas of her past she did not want to revisit. She felt

all this work impacting drastically on her life. She gave away study, abandoned interests and professional responsibilities. In the meantime service providers wouldn't make commitments until they knew how many hours would be approved by the NDIA.

"Because at every stage when I gave them (NDIA) the benefit of the doubt, they kept on betraying me and my situation. So I have realised my best hope of getting a good outcome was for me to do this work but I have no sense that it's actually going to work."

"in the end I had managed to keep each of the sections to the 200 characters (limit) by carefully editing and editing and editing. And I am producing a background document which is now 35 pages. Because I built it up, one idea at a time. You know it is just horrific"

At the time of the interview, Diana felt that she was days away from submitting her Plan and was living in "utter fear" of the outcome. She is very clear that the NDIS is a worthy scheme however her concern is its implementation.

"I can understand that some of the mistakes they have made may be teething mistakes, training mistakes, whatever. But it is out of control."

Her other concern is for those who will seek to enter or participate in the scheme who do not share her administrative background, ability to research and self-advocate.

Sophie

Sophie is a young woman who has experienced some big changes since her NDIS Plan was approved and implemented. She lives in supported accommodation and her Plan is managed by a service provider. Sophie also has an independent advocate who has assisted her in formulating life goals, other aspects of her Plan and life in general.

Sophie and her support worker met for an interview and discussed the changes that are happening in Sophie's life. Sophie said she can now choose which activities she does. In the past service provider staff had upset her and she didn't want to continue with them but she didn't have a choice. Now she has left these services and has been trialling others. She continues activities she likes and doesn't return to the ones she didn't like.

"I'm still choosing"

One of Sophie's goals is to move out of supported accommodation and home with her Mum and Dad. Both her advocate and case manager are supporting this. She would also like a job. The support worker and Sophie have been visiting organisations where opportunities may exist.

Although Sophie wasn't familiar with what the NDIA is and appears not to have been heavily involved in the actual paper work, she clearly understands there is now 'grant money' available which allows her to trial and choose services.

The service provider who manages Sophie's Plan was recently approached by the NDIA to take her as a client. This provider has a Plan Coordinator who helps the clients with their packages. Sophie said her favourite thing to do was to *"do something with Kate"*.

Maria

Maria lives with and cares for her sister, Lorraine, in their family home. Her youngest son, in his twenties, also lives with them. Maria also supports him in many facets of his life. Maria lives with and manages her own disability which she rarely discloses. She is yet to engage with any disability service for her own support.

Maria first made contact with the NDIA on behalf of Lorraine. Maria had ensured Lorraine's eligibility very early on which she found a straight forward process.

"Yes I guess that was fairly easy, it just meant extra work but it was; yeah that was fairly easy for me because we've had the same GP for a really long time, so she knew us.."

She attended community forums during 2014.

"Bits and pieces were useful but generally I don't know, I found them a bit - I wouldn't say it was a great meeting, it was only bits and pieces"

"Questions that I really wanted the answers to they didn't really know, you know? That was a main theme at the time that I went".

"I remember the last meeting they had lots of planning forms which I thought was good and I could see that some of them were typed up in a more simplistic form, in a simplistic way so I grabbed a few of those but what I ended up doing was I was working on the one that the NDIS recommended."

From there, she worked tirelessly, to complete the paperwork. This experience proved incredibly stressful. Maria isn't sure exactly why it was so worrying but puts it down to service providers and voices at the NDIA meetings emphasising that she had to *"get it right the first time or you will miss out"*.

Maria discussed the participant's statement with Lorraine. It was challenging as some of the concepts were hard to explain such as life goals and their significance.

"I'm doing it for Lorraine, and I'm sitting there and I'm explaining to her what I am doing and I'm getting her to answer as many questions as I can or getting her to think and stuff but I think it was just annoying the hell out of her. These days I realise I've got to pick my times when she's not tired. That was a bit frustrating."

"That was the initial application and I think I was so stressed about getting it wrong because I felt so responsible"

The forms provided by the NDIA were not simple for Maria to complete.

“my background was the office, it was a long time ago, I have not been in the office so I can't say I'm great at writing or when I actually started with the form I answered the first two questions and then I went onto the next question and I'm like oh no, I've already answered that question because they're saying the same thing to me”

She sought support in completing the paperwork from a service provider she had a long term connection with.

“honestly in hindsight it must have just been all this blurb and stuff but you know how, I've realised my process is the draft and then going back and actually refining it, making more sense of it and getting rid of all the repetition. She was really patient so I'd email.”

“in actual fact I just wanted her to do it really. I'm like anyone please - I just want someone to do it”.

One of the hardest parts for Maria was to assess her own role and what support she provides to Lorraine.

“Lorraine has been a part of our family since my first son was 18 months old and so generally I just get on with her and haven't even thought about it and I don't know, its only been of late that I've thought about the consequences of my carer role, I think it's because it's increasing and anyway that was really hard for me, probably good I guess”

Maria got to the stage where she finished the form and was happy with what she had done only to find out that she had to re-do it. The form she picked up from the meeting had been updated.

She finally lodged the forms via email, more than 6 months after she commenced the process.

“I felt like I spent six months of my life - spare time, working on the form. I know that sounds crazy”.

During this time Maria hadn't had any contact with the NDIA staff. The first meeting with a planner was arranged and Maria was pleased the NDIA staff agreed to meet her at her choice of NDIA office.

Lorraine and Maria attended the meeting together. Although Maria was incredibly nervous, the NDIA planner was supportive. She seemed to understand Maria's own situation living with a disability as well as generously devoting considerable time to providing Lorraine's supports.

“That was pretty good because she did seem to understand (Maria's disability). I think that was the positive part about the meeting, I think she was fairly generous with Lorraine's needs. There wasn't an issue about any of her needs not being met.”

“And she whipped it up (Lorraine's Plan) in that meeting, the whole thing, so I've got a feeling we must have been there for two hours and I felt that she seemed pretty good actually, she seemed pretty supportive.”

The length of the meeting was arduous. It didn't take long before Lorraine became very tired and could not participate in the planning. Maria was also a little frustrated as she realised the planner was rewriting their documents into another template and then asked to keep Maria's form at the end of the meeting. She wasn't sure why all this needed to be done with them sitting there.

Lorraine's draft Plan was almost completed in that first meeting. The second meeting was scheduled for three weeks later. In that time Maria emailed the planner a few times and some changes were made. Maria was especially concerned about the transport allocation for Lorraine.

"I found it really hard to get answers because I don't think she (the planner) knew the answers and she did say this is a trial and things are going to be a bit slow and there are grey areas. I sort of thought she can get all the answers from me, why can't I have all the answers? I was a bit frustrated."

"There were those little things and I was really stressed, she could tell. I think she made the comment that she didn't understand and I'm like I don't know. If I mentioned ... about the pressure, doing it for someone else, but yeah, it was pretty full-on. I don't think I left anything out really and then we were going to have this next meeting. ...I was in a panic about the agreement; I can remember that, being in a panic about doing this agreement."

At the next meeting they recapped what was in the Plan. Maria couldn't be sure Lorraine really understood what this discussion was about and felt sorry that she had to sit through it all again. Some positive aspects of the discussion were that Maria nominated a coordinator for Lorraine's Plan; elected not to self-manage the fund to decrease her stress levels; changed many of the activities Lorraine does and organised service providers. Extra hours were allocated for home support which also decreased Maria's workload. Maria also asked for some minimal time to be allocated for a handy person to attend their home.

"So the only issues was [sic] transport and she wouldn't give me a handyperson. Honestly I just wanted one or two hours a year because no one can use a drill, we don't have a drill and she's like, if you've got a male living in the house they are assumed and I'm like – I just didn't say anything because I was too pooped."

Maria signed Lorraine's form in that second meeting. She was surprised it was moving so quickly.

"I was planning on bringing it home and reading it but she (the planner) talked me into not because she just wanted to get it done, she was a taskmaster I'll tell you and she was generally nice but she was really focused ..."

Since the Plan was approved the implementation has been slow and frustrating, for the first time in many years Maria and Lorraine weren't getting along.

"Lorraine started getting depressed and I felt like I was going crazy in some respect. Sorry for using that terminology but because things were too slow and things weren't happening, that meant I wasn't getting a break, Lorraine was doing less, so I feel like it's taken til now, like six months for those things to be put in place and the changes to be made."

However many aspects of the Plan have had positive outcomes and improved both Lorraine's and Maria's way of life. Lorraine is now happy with her new support workers and outings. The quality of support has improved. Maria was given some carer respite and the additional provision in cleaning is greatly beneficial. To work around the limited transport funding, Lorraine's activities are mainly in-house. This disappoints Maria as she knows how much Lorraine likes getting out into the community.

At present, Lorraine and Maria are settling in to the changes and feel positive about their current situation. Maria believes she can contact the NDIA planner if changes to Lorraine's Plans are necessary. She doesn't use the portal regularly but asks the plan coordinator to view it for her when she is feeling overwhelmed or busy.

Towards the end of the interview the researcher asked Maria if she would ever consider going through the process again in regards to her own situation.

"Not really, she (the NDIA planner) said have you ever thought about going on Disability [Disability Support Pension] and I'm like look, I don't know. In the end I decided I didn't want to because my needs weren't that great, or not as great as – I don't know, that's honestly how I saw it".

Overall Maria is disappointed that the process of developing Lorraine's Plan was so stressful however feels like the NDIS is a great opportunity and an excellent scheme. She hopes that others can really benefit from what it has to offer.

Margie

Maintaining independence and dignity are crucial to Margie's wellbeing. She wholeheartedly hopes the NDIS can support her to preserve these qualities into the future. Over the past year Margie has been researching, gathering evidence, planning, thinking and educating herself on how the NDIS can best support her.

Part of this process was attending the Choice and Control expo in 2014 where by chance Margie signed up to the Catholic Care newsletter. Despite the organisation not being one of her service providers; this contact has been crucial. Catholic Care have informed Margie of many essential details, information she expected would come from the NDIA but did not.

"the only way I found out that things were happening was through Catholic Care newsletters"

These newsletters informed Margie and her husband of a pre-planning meeting in October 2014 which they attended.

"It was (useful) to a degree but I asked very specific questions and they promised to get back to me on them and they never did so that was very disappointing"

Margie completed "My Access Checker" towards the end of 2014. This was straight forward. She then began collecting the evidence to contribute to the "Evidence of Disability Form". Due to her highly complex medical situation where a team of specialists are providing support, collecting this evidence according to the NDIA's requirements was going to be arduous for everyone involved.

"At the beginning of it, it says "list your primary chronic condition" and that rang alarm bells straight away because I haven't got one primary chronic condition."

"He (specialist) told me he was not familiar with how the NDIS worked, as I might add, did the rest of my medical team"

An NDIA team leader agreed it would be best to have Margie's long-term GP collect the information from specialists and collate it for the NDIA. This also avoided the impossible concept of identifying Margie's "primary condition".

"It's an enormous task just for her (GP) and so what I was asking for was to write to all the people who support me and get a letter outlining my diagnosis and the impact they have on my life. This turned out to be a very positive approach but meant lots of work..."

Collecting this information took over four months. She lodged the "Evidence of Disability form" just before the due date. The next day, she received a curtesy phone call from the NDIA asking if she would like to join the NDIS and letting her know she needed to lodge her "Evidence of Disability Form" in the next few days. Luckily she had been working on it for the previous five months.

Not long afterwards Catholic Care shared the information that NDIA had participant grants available. Margie was feeling overwhelmed at the prospects of completing her participant's statement, finding service providers, the timeframes, the lack of benchmarks provided by the NDIA and thought a life coach would be invaluable assistance.

"I was brutally honest but I got the grant"

Completing the participant's statement has been confusing and a huge workload.

"then I had this form that the NDIA had sent me, or was it on their website, and it's the old type of form and I'd filled it in to start off with and because there are so many forms and it's so confusing but they want all this information. It's information they require, its 20 pages, it killed me.."

"they want to know about my family, my children, and I mean I find it so intrusive. I just find it awful...friends – they're wanting – they presume that your friends are going to take you to medical appointments, take you shopping, take you to the hairdressers...it's a big intrusion on my life."

Margie and her husband worked tirelessly on her participant's statement. Her life goals are clear, inspiring and balanced. Margie changed the format of the statement into something that she could better interpret and work with.

"It wasn't until I turned my plan into a "PowerPoint presentation format', I could then start to succinctly, with the help of my husband, list key points under each goal. I am a very visual person and this worked best for me"

Without any benchmarks to work against Margie found it incredibly difficult to determine what supports she could request. She feels she will have to limit her social participation due other expenses.

"I'm not asking for much in the social life because I mean, my whole life is taken up with my medical problems"

Margie is right to point out that many of her social activities are essential for her wellbeing. She is concerned the NDIA may not value her pursuit of those or alternative therapies.

"I spoke about doing the mindfulness course, he (NDIA staff member) said he's not sure if this could be funded under the NDIS and I would need empirical evidence".

The area of transport was especially concerning and time consuming.

"(My husband) put together this amazing spreadsheet and try and find NDIS codes which match this and we have to learn to be creative because the transport allocation, just to see my medical team... won't even cover, I won't even get out the door."

"Since my husband has retired he's spent too much of his time transporting me to appointments and this is not good for our relationship"

"Yeah this is just a nightmare and then my husband has counted it up and just the transport costs and everything else, he says you're up to so much money and I say well what am I supposed to do? I mean am I entitled to these things, am I not entitled to these things? I don't know, are they just going to go bang, bang and cut half of them away?"

Margie has been working tirelessly for months to get to this stage and emphasised the difficulty in finding support in this process.

"They (NDIA) send out an email with all these forms attached and say this is when your first meeting is but not once do they ring up and say well come in and we'll guide you through these forms."

"My biggest concern is for those who haven't the skills or background of my husband and I, they will be railroaded into accepting very little."

Support has come primarily from her husband. Before she was given the grant, Margie had approached two organisations for advocacy support however one was already at full capacity, the other only agreed to advocate if she nominated them to provide support services in her approved Plan. With the grant money she was able to engage a life coach.

"I've joined a few Facebook sites as well, NDIS Grassroots and things like that...they have been (useful) because you're listening to scenarios and reading, and then they're suggesting different..."

"it's an impossible task to do alone"

Margie has her first planning meeting soon. She has heard that once the first meeting is held things could move quickly.

"due to their KPI's and their workload, they want it done in about one or two meetings."

"so that's the approach, that's the rationale around why I'm doing it this way because I know that they (NDIA) can't cope with it."

While Margie has been setting aside many important things in her life to concentrate on her application and planning, her usual support services have also declined.

"My current service provider... who has assisted me for over five years can no longer provide all the services they used to.... I've been told I can't get any more help... they haven't got any money....I've gone without assistance in some of these areas for over six months."

Margie was told this change of service was due to the organisations having their funding cut for potential NDIS participants. She acknowledges this needs validating but is concerned about funding arrangements between the federal government, HACC and the NDIA.

Once her Plan is approved, Margie is aware there is still a lot more work to be done.

“After we go through this battle we then have to set up service agreements with all these different people and negotiate. I want to trial these people; I don’t just want to enter into long-term relationships”

Margie got in touch after her first planning meeting to give some further feedback.

“My husband and I... have responded to many federal government tenders. We felt like we were responding to a government tender with no formal guidelines. We were making adjustments to my plan on the morning of the meeting when suppliers changed pricing schedules.”

“I am a visual person, couldn’t understand the NDIS planning form, so made up my own. My NDIS planner and “Life Coach” had never seen a plan like this before and the NDIS planner said it was the first time she didn’t have to take notes. All the information was there for her, in a ‘display folder’, with detailed information behind each of my six goals”

Keeping her dignity and independence at the forefront, she had developed a document “Who I am” to take with her to her the meeting.

“I wanted to introduce myself to the NDIA planner and be not just seen as a ‘number’. I also wanted them to see what personal opinions I held in certain areas.”

Although the workload was almost unbearable Margie is philosophical about the process.

“I am happy with what I presented to the NDIS ACT as I feel I spent the time really evaluating how I would like my future to be. I have no idea how successful I will be this time round, but now have a vision for the foreseeable future.”

Belinda ⁴

Belinda began contacting the NDIA for two reasons, firstly regarding her eligibility as a Participant and also to apply for a job. She rang the NDIA and believes the contact she had was condescending and inappropriate.

“A woman talking very slowly in a high pitched voice, the kind you talk to little children in. Offensive, inappropriate, disrespectful.”

She has also visited the office to provide evidence of her disability as well as feedback of her experience so far. She is most concerned that unsuitable interview spaces have been provided. The NDIA staff member sat on an ergonomic chair and left an inaccessible chair for Belinda.

⁴ Information provided via email

“The woman said “you can sit on your walker”...I looked at her in horror”

This experience was repeated the next time she went into the office ten days later.

Recently she has needed to attend the Braddon office for job interviews with the NDIA. This has been challenging with limited parking and a shortage of information about location and access to the building on the NDIA website.

“I went for a job interview on Friday (with the NDIA). The interviewer rang me the day before, when I told him I had trouble finding the office, he said “use a GPS”. As a disabled person forced into abject poverty (for nearly 20 years now) I do not have a GPS because I can’t afford one.”

Belinda is very concerned that many of the NDIA staff members have not received sufficient disability awareness training.

“It became clear to me that while the NDIS is trying to establish a good culture, employ people with the lived experience... I assume a number of their employees....have not received adequate disability awareness training, or fail to be mindful at all.”

“Perhaps the easiest way of looking at this is that these non-disabled people are trying to work with us, but in order to do so they must understand our world, be aware of the reality of disabled people’s lives and confront their own negative hatreds, judgements and fears...”

Insights:

The seven women who have generously shared their stories provide an invaluable insight into opportunities and challenges presented by the NDIS in the ACT. The women’s stories articulate issues which were important to them as individuals.

It should be noted that some aspects of their stories have been echoed in other forums and jurisdictions which perhaps suggests that they are not limited to the seven participants of this research.

There is cross over with some of the issues presented in the NDIS Citizens’ jury report which was completed in February this year. Including:

- participant’s sense of choice and control and improved options for services;
- the need for the NDIA to provide more upfront information and in a variety of formats,
- further training of staff
- the need to revamp the NDIA website.

Information around the NDIA in the ACT was also gathered at the community forums WWDACT hosted in May this year. During the forums women with disabilities discussed key issues around their health and wellbeing, including housing, education, and community participation. The NDIA was raised in numerous conversations. The overarching concerns being linked to:

- eligibility,

- complaints processes,
- overwhelming pre-planning processes and
- disruption to current services due to the NDIS trial.

The detailed report on the 2015 WWDACT Forum outlines these conversations in greater detail, and can be viewed online at <http://www.wchm.org.au/wwdact/>.

The article that first inspired this research, *“Bureaucratic ‘gobbledygook’ fuels National Disability Insurance Scheme”* also highlighted many similar issues for participants and their families which have been raised by the women in this research namely:

- funding for transport,
- confusion over forms and templates,
- knowledge held by the NDIA staff on different disabilities.

From the researcher’s point of view the women interviewed for this project have clearly explained their key concerns and these should be considered in the context of that individual. However there were some key themes that stood out during the research process.

1. Support for the NDIS

Many of the women were very supportive of the NDIS. They thought the scheme offered wonderful new potential for an improved quality of life. All three of the participants that had been involved in having Plans approved agreed that many services and supports had improved and they had experienced genuine choice. Those who held reservations on how the NDIA is operating were clear to make the distinction between the NDIA and the NDIS.

2. Stress and workload

It was obvious that many of the women had experienced overwhelming amounts of stress in gaining eligibility, planning and implementing Plans. Women were visually upset discussing the anxiety and pressure associated with their experience. On top of this, the workload required to complete the process had meant many important aspects of their life had been put on hold. This sense of exhaustion had also led them to ‘not rocking the boat’ when they had wanted to question the NDIA’s actions or decisions.

3. Support

The need for support was voiced by all those who had been involved in developing a plan. Support from community organisations and online forums for information, but most significantly the role of independent advocacy was regarded as an essential component and should not be underestimated.

Three of the women did months of planning without any contact with the NDIA. They had all experienced high levels of stress and concern during this time. It seemed there was a missed opportunity to develop a positive relationship with an NDIA planner to support and guide them through this process.

There was genuine concern shown for other women with disabilities, querying how others were going to cope transitioning onto the NDIS. The interviewees questioned how others would cope

with the workload, the complexities, and the long process without strong self-advocacy and administration skills? There was worry there is not enough advocacy support available.

Two of the interviewees expressed concern about the NDIS planner making the assumption that the individual could call on “natural supports” for some of their activities, even though these natural supports were non-existent. The women did not feel they had a strong network of family or friends on whom they could call for assistance. Lack of connectedness is common for women with disabilities⁵.

Two other themes were discussed by women and are of particular interest as they have not come up in other readings.

GP and specialist involvement was obviously an integral part of the eligibility process. Participants in this research were unsure about the information that had been provided to their medical practitioners about the NDIS and their expected role.

Assistive technology assessments were highlighted as an exciting and essential part in developing a Plan. Women put a high priority on provision of appropriate technology as part of their Plans.

The NDIA’s strategic Plan outlines the agency’s cultural values:

- Assurance
- Empowerment
- Responsibility
- Learning
- Integrity

These values should underpin all actions and interactions. Overall there have certainly been incidents where NDIA staff have demonstrated these values, building trusting and meaningful relationships and ensuring high quality supports to enable improved participation. From the women’s experiences, there is still some work to undertake until these values are central to all interactions.

Conclusion:

The NDIS is a very new and complex scheme with highly positive and life changing outcomes on offer. There is no doubt the job of the NDIA is challenging and enormous, impossible to avoid teething problems and initial bumps. Women who participated in this research were enthusiastic about the Scheme and those who had begun implementing Plans had experienced positive changes. However, many women could not understand the levels of stress and complexity which accompanied their interactions with the NDIA.

The women have voiced their specific experiences in the context of this trial phase. As the trial progresses and the Scheme is ‘rolled out’ it will be necessary not only to follow the NDIA’s activities in the ACT, but also that of service providers and community organisations. Further research will be essential to ensure the NDIA delivers this important Scheme to the highest of standards.

⁵ Carnovale, A.; *Strong Women – Great City*, p.25, WCHM & WWDAC, 2012

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APPENDIX A

Bureaucratic 'gobbledygook' fuels National Disability Insurance Scheme anxiety

Date

March 27, 2015



Clare Colley

Reporter at The Canberra Times

Bureaucratic "gobbledygook", a lack of respite and transport funding, and inexperienced planners are just some of the problems creating anxiety around the National Disability Insurance Scheme, participants have told a public hearing into the ACT roll-out.

While some had positive comments about the life-changing scheme, the bulk of the evidence before the joint parliamentary committee was negative with complaints of lengthy waits for assessment by planners with little knowledge of complex disabilities.

At times emotional families told the committee they feared their loved ones would be left worse off as the NDIS takes over disability service provision.

Several participants and providers spoke of the "gobbledygook" used by National Disability Insurance Agency planners making it difficult to understand the criteria to gain support

ACT Disability, Aged and Carer Advocacy Service chief executive officer Fiona May said the organisation received many calls from participants overwhelmed and confused by the volume of information and jargon.

"We have raised with the agency [NDIA] that we're concerned the Plans are incomprehensible to people," she said.

"The templates and processes are not easy to understand and the new language ... creates a significant barrier for people to argue their case successfully."

Ms May said she knew of one family whose access was arranged exactly within the 21-day period and another still waiting after five weeks.

NDIA general manager Liz Cairns said 12 of the agency's "most accessed" documents had been translated into easy English on its website as of Friday, but admitted the planning documentation was yet to be revised.

Committee member Jenny Macklin said it was a serious problem that had to be addressed.

Ms Cairns said work was ongoing to simplify the Plans and provide more flexibility for participants to choose where their money was spent.

Autism Aspergers Advocacy Australia convener Bob Buckley was one of several people who raised concerns about the "variable" knowledge of planners.

Ms Cairns said there was a "robust" quality assurance framework, but admitted planners had "varying degrees of expertise".

Ms Macklin said planners appeared to be under "enormous pressure" with data suggesting they were failing to meet targets.

She questioned whether there were too few in the ACT.

But the NDIA's ACT manager Jillian Paull said the ACT was one of only two sites to meet its second-quarter target.

The NDIA's Alice Tibbets said the agency was advertising for more staff to cope.

The committee also heard of discrepancies in the amount of funding for participants with similar needs.

Just Better Care owner Fergus Nelson was one provider to cite examples where participants had "undoubtedly" received more than they needed while others were left deflated after coming away with little or no funding.

Committee member Senator Zed Seselja agreed and said a provider had told him the amount of funding appeared to hinge on the participant's ability to explain their needs.

But Ms Paull defended the packages saying the agency was "pleased" each Plan was unique.

"It isn't useful to say there are two children in the world who have similar needs and have different looking packages for different amounts of money because that's a gross oversimplification of the process," she said.

Several participants and providers complained of a reduction in respite hours for carers.

Ms Tibbets said the agency had heard the concerns and were in discussions with the pricing team about introducing an evening, overnight and weekend respite rate for children.

Others criticised a policy to strip 20 minutes from each hour of care to cover transport provision.

"Everyone loses out, the client gets 20 minutes less, the worker gets paid 20 minutes less and the providers are bearing the brunt of it," DUO Services chief executive Cheryl Pollard said.

Ms Cairns said the concerns would be addressed in ongoing pricing work, but said it came from advice from independent experts.

Several carers said planners had limited the amount of transport funding available in each Plan.

Ms Cairns said there was no cap, but the guidelines were "frequently misunderstood".

APPENDIX B

Interview Questions

What is your understanding of the NDIA?

Can you outline the difference between the NDIA and the NDIS – today we are mainly focusing on the work of the NDIA

Can you tell me what sort of contact you have had with the NDIA?

The information provided by the NDIA, has that been useful?

What evidence was needed for eligibility testing?

Did you need help to gather this evidence?

How did you feel beginning to develop your Plan?

What was the process of developing a Plan?

Did an advocate or anyone else help you with your Plan?

Have your service providers changed? Either organisations changed or the type of service you are requesting?

Did you feel like the NDIA planner understood your situation and needs?

Did you choose to self-manage your fund? Why/why not?

Were you satisfied with your Plan when it was approved?

Once your Plan was approved were you clear on what to do next?

How would you describe the staff at the NDIA?

What are your thoughts of your experience with the NDIA so far?

The NDIA often use words like CHOICE and CONTROL – do these reflect your experience?

Do you feel your levels of independence and participation have changed since your interactions with the NDIA?

How can the NDIA improve itself?