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My Experience of NDIS - Thus Far

Hello! I am Tricia Curley a participant of the National Disability Insurance Scheme. My First Plan was developed in 2014.

I live in Newcastle in the Hunter Valley NSW. We were designated the first of the four Trial Sites. Everything was New - the NDIS hype.

My Story:

Preparation:

I began my preparation by familiarising myself with the:

- Productivity Commission's Inquiry Report - Disability Care and Support No.54. 31 July 2011, Overview and Recommendations - Volumes 1 & 2.
- The National Disability Insurance Scheme Act 2013 No. 20, 2013 and
- the online website for NDIS

The exercise of articulating what would give me a good life was something I struggled with. I, like most people who live with disability in their life, live below the poverty line.

We are not included in everyday society so it is unfamiliar to consider what would give me participation and inclusion. I was also to have this, most personal conversation, with a stranger employed by the federal government. I preserved and printed out my goals.

I attended the meeting alone. Although I was a client of Vision Australia they were not assisting or advocating for us in the NDIA processes.

I went into a sterile room with a male employee. He went over the process then I was to talk about my goals. I spoke about how I had been isolated for seven years because I could not get paid work and transport is costly.

As I spoke about my aspirations and goals he kept explaining that what I wanted did not fit the scheme. I argued that my goals were both reasonable and necessary for me to have a "normal life". He continued to outline what he felt would be better for me and started documenting that. I felt I was not making my own decisions so I got up and as I left I was crying.

My first plan was not what I wanted. I tried to make it work for me. The transport money gave me the opportunity to move out of the house. I began to attend community meetings where I met new people.

My second plan was different in that I worked with a friend who helped me to align my goals with NDIA so I could work toward some of my goals.

The plan meeting was at my home. The NDIA planner came along with another worker. When seated she wanted my completed forms. I did not have the forms completed because I couldn't read or fill them in. However I had set out my goals to fit the structure of the forms.

She was not impressed and insisted that I answer her questions and filled in the forms she brought with her. At the end I had a little time to talk about my ideas. By this time I felt very uncomfortable and just wanted them to leave.

With this plan I learned I didn't have to cut my toes anymore. I got some podiatry in the plan. This is just such a great change.

She also left the travel in so I began to achieve my goals despite not having appropriate technology to help me. I began attending a course. I was not able to overcome the barriers of not having technology - I could not access the course material, the presentations or take notes during class times. I was forced to give up.

I spent a long time, over 200 hours, preparing my third plan. I read everything published, attended every meeting available and talked with everyone who had the time to share their experience of NDIA.

I removed the goals from a copy of my second plan and inserted my new goals and aspirations. I was now a client of the Royal Society for the Blind and my plan meeting was held in their offices with my OT as support and backup.

I presented my planner with a printed copy, a digital copy on USB and I emailed an additional copy. I received a really good plan and I was so looking forward to beginning to achieve my goals.

I got three months work with a community organisation just after my plan was accepted. The job was intended to give me a current work history and referees. As this ended my support coordinator had to leave. I took a little time off to adjust.

I set to employing staff to help clean the house and yard. It was a struggle to get workers that would come to a housing commission area and work for only an hour or so.

I became aware that RSB was paying my bills because the NDIA Portal was down. This continued for months. RSB was new to Newcastle and they were trying to establish themselves. I was so concerned that I was impeding access to their services for others because they were paying my bills. I managed as I was and did not try to employ additional supports.

My plan manager left so I had no contact person for some time. I found having to keep trying to do the additional cleaning, keep shopping on my own and trying to achieve my goals without assistive technology was making me very stressed.

I began to attend psychology appointments to discover I was depressed and anxious. I was struggling to get back on track with employing additional staff.

I had achieved a number of my goals in that I have developed an extensive network of contacts for work, I have joined U3A and Hunter Writers Group where I attended courses on communication and writing.

I have attended and graduated a Peer Mentoring course. I have mentored a number of mentees.

I am making connections with people who share my interests and I now have people to talk with in the courses. RSB now has an interim worker who comes to Newcastle two days a fortnight. She explained they did not want to plan manage me anymore because it was too costly.

I have commenced cane training, how to use a Victor Stream and an iPhone. I have attended the apple store at Charlestown to further develop my skills - community inclusion.

I regularly attend community groups and I continue to build my employable skills.

The transport has meant I can go out when I want to. I have been to Newcastle beach to enjoy an hour watching the waves, I attend my courses in writing and developing thinking skills even when the venue changes. I can offer my neighbours a ride home from the super market.

A couple of weeks ago, on the really wet and stormy day I could give an elderly gentleman (91) a ride from the library to Wests so he didn't get wet. The taxi driver took him into the club. It's so nice to be able to help someone.

In February I was contacted by an NDIA employee to have my plan review early. I tried to ask for it to be rolled over as I had not been able to fully activate the plan. I explained about the portal being down for months which was experience by a large number of service providers.

This person would not consider this and proceeded to state I was to be reviewed by phone. I asked where the person centre approach had gone. She explained that there had been some amendments to the act. I was shocked and angry that, as a participant, I was not aware of the changes. She became angry because I was upset.

I found out about my plan review date from the RSB interim worker. I went to the review with my goals ready to discuss my next year. The plan manger and I went into a room where the worker spoke predominantly with my plan manager. I found out they had been communicating without my knowledge.

I attempted to explain my plans for the coming year. I was told my plan would be reduced and the decision would be made by an employee of NDIA who is blind.

The worker indicated that I did not meet the bench marks. I questioned what the benchmarks were. The worker proceed ending the meeting speaking with my plan manager. We left. Outside I asked the RSB worker why she did not refer the NDIA worker to me instead of having the conversation about me.

I currently have a plan that has required me to withdraw from my acuities and I don't have adequate support to assist me to reduce my level of stress. The plan is a third of the previous plan.

Although my journey with NDIA has not been the best I still vehemently believe that if NDIA could be supported appropriately and developed to its full potential there is the opportunity for future generations of people with disabilities living full inclusive lives.

My Suggestions

People living with disability in their lives have never been included in the wider community. They continue to live on a below the poverty line income while their expenses are more than four times that of a person of the same age.

The extra cost stems from the requirement to have - appropriate/flexible supports, assistive technologies, appropriate/affordable housing, access and resources to attend education/employment, access to community facilities, access to services and appropriate/affordable transport.

To redress this level of disadvantage will take two or three generations for individuals to develop a new mindset and a toolkit of skills and abilities to take a valued role in society.

The alternative to not achieving full inclusion is going to be costly to everyone in so many ways. We are people who share aspirations, dreams, and goals we wish to achieve. Those of us who are able to work only require employers to recognise the value of our lived

experience, make their workplaces fully accessible and reap the benefits of employees who desire to build a career path as well as their businesses.

These need to be acknowledged:

- most people with disabilities want to be included in the life of their communities
- most people with a disability have never been able to make choices let alone life choices
- most services, facilities, education, employment, housing, transport and health services need to be made accessible and flexible
- the government publically recognise the employment generated my participants
- participants attend face-to-face planning meetings
- recognition that most of us live below the poverty line

Person Centred

- in person plan meeting if desired
- disclosure on internal changes within the operation and service provision of the agency
- regular participant meetings with NDIA staff to disseminate information and capacity build
- participants and non-participants to be on the board
- participants be employed to assist service providers to develop flexible and approximate service models
- reverse reasonable and necessary to necessary and reasonable
- open access to assistive technology to the wider community to develop new business pathways and reduce costs

Regards
Tricia