

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Name: Name suppressed
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Partially
Confidential

I am the mother of a disabled 26-year-old son who has Beckwith Weidemann Syndrome. I suffered emotional abuse as a child and then spent 34 years in an emotionally abusive marriage. As you can imagine I suffer horrifically with depression. A year and a half ago I left my husband and it was then that I realized that not all of our problems were my fault. He spoke badly to s well so I decided to take and make a better life for us. We are renting a unit together.

disability affects the mainly the front lobe of his brain, He has difficulty with planning motivation expressing himself and needs lots of prompting with self-care to name a few difficulties. is 26 and wants to be independent of me, but he doesn't have the skills needed to live on his own. He gets very frustrated and that frustration turns to anger which he turns on me. He has never hit me but has punched the wall beside my head and yells and screams at me. He has also picked up some of his father's habits in the way he tries to control me. He thinks this is being the man of the house. So I am constantly walking on eggshells around him so he doesn't become angry with me. I thought when We moved into the unit that we would have a good life together but now I am in fear that when he is angry that he will hit me.

Most of the time is the most a very gentle person and his very gentle and well behaved with anyone else. I can't cope with him anymore and the NDIS who is supposed to provide support isn't supporting at all. Before the NDIS we had difficulty getting funding for in the right areas but with Northcott, we had to coordinate for him and I could go to her and talk over any problems and we worked out solutions within the funding limits. I was told that the NDIA would be fantastic for as he would be funded for what he needs and we would not be worse off.

THAT WAS A BIG FAT LIE.

Since the NDIA came in I have lost my coordinator. I am expected to manage funding myself and not given the proper tools to do so. funding used to help with fuel so he could drive to tafe as catching public transport is difficult for him. This has also been taken away from us. I have been constantly pleading with Northcott for more help and have been told that because has no coordination funding they cannot speak to or support me. I have also been pleading with with the same effect. My first LAC didn't call me and would not answer when I called her and then complained to the NDIA that I was not contactable. I was devastated.

After making a written complaint was given a new LAC name . In the beginning, she spoke to me but did not help me at all. She did request a change of circumstances review last November. When we hadn't heard anything by February I rang her and she told me that it was up to me to find out where the request was up to so I rang the NDIA and was told that it takes 4 months before they even look at the request. I pled with them to speed up the process as I am not coping. My plea fell on deaf ears.

Finally, we had the review but will it take them another 4 months to look at that review. In the review we have also asked for accommodation funding so that can live on his own with the support he needs. j I am too scared to hope that some good will come from that review.

In the meantime, my health keeps getting worse. I just want out of life because I can't cope anymore. I have difficulty walking as my ankle joints continually swell and become painful, I have arthritis in my hands which is getting worse. I have mild emphysema which is worse when I am stressed which is all the time now and no one cares about or myself. I am constantly crying. I don't know what to do anymore. And to make matters worse the government is taking away the little bit of help I had in the form of home help 1 hour per week and now that is being taken away from me. I applied for NDIA funding and was turned down with a nasty letter.

Talk about kicking a dog when it is down. My life has become awful because of the NDIA please make it work properly or disband it.