

Personal Impact

I am a mother of three children aged 3, 2 and 10 months. My middle child has multiple disabilities and is a Participant of the NDIS.

I have exhausted both my informal and community supports and am now turning to complete strangers to babysit for me for free so that I can get my dishes and folding done, yet I am expected to prepare, attend, appeal, research, investigate, manage and pursue endless emails, phone calls, meetings, committees, politicians, planners, service providers, banks and more in order to just try and secure what my daughter already had before becoming a participant of the scheme. Not to mention implement my daughters medical and therapeutic needs, and the regular commitments to my other children.

I do not meet the income criteria to receive Carer's Payment to alleviate the pressures of domestic duties despite having had less than \$20,000 income for the past 9 months.

The transition from the old system to the new has taken its toll emotionally and mentally on me.

It has been more stress, pressure and workload than anything I have faced previously.

I'd like to take some time to tell you about our experience with the NDIS.

My daughter has:

- Optic Nerve Hypoplasia and is severely vision impaired.
- Pituitary Hypoplasia (underdeveloped Pituitary Gland) and is medicated twice daily with synthetic hormones
- Fenestrated Falx (incomplete fibre connecting 'halves of the brain')
- Absent Olfactory Nerves (no sense of smell)
- Volume loss of the left hemicebre (left half of the brain)
- Heteratopia (abnormal brain layering)
- Polymicrogyria (irregular surface of the brain)
- Intracranial Cysts
- Asthma

Her diagnosis is:

- Septo Optic Dysplasia
- Diabetes Insipidus
- Suspected other syndromes, yet to be identified

Current Medications:

- Desmopressin (morning and night)
- Thyroxine (morning)
- Flexotide (morning and night)

Juno Cannot:

- weight bare on her legs
- effectively roll from front to back or visa versa
- sit up from prone, or visa versa
- self feed
- tolerate any solid food and is still on a pureed baby diet
- tolerate everyday experiences like a scarf touching her hand, food touching her clothes, socks or shoes on her feet and even particular items of clothing against her skin without gagging and vomiting
- be touched by people other than myself, a select few family members and therapists
- tolerate noises beyond a quiet and calm level without meltdowns
- mobilise in any other way than by bottom shuffling
- navigate steps or slopes
- walk or crawl and needs to be carried
- sleep through the night without waking numerous times
- control how much she wees and wets through her nappies and clothing on a regular basis
- perceive her surroundings visually and so relies on touch as her primary sense
- communicate with words

Planning Process

- It was an inconvenience for me to arrange a babysitter for 2 older children and take exclusively breastfed baby all the way to St Mary's (1.5hr drive each way from Gumeracha) for a 3-4hr Planning meeting on 23/1/14. I was met with reluctance for it to be in-home and told it was 'preferable' for it to be in the office.
- I felt my treatment during the planning meeting was disgusting. I wasn't listened to. I wasn't heard. I wasn't allowed to discuss everything I'd brought with me. I was told "stop, I'll be asking the questions" with a hand put up to my face upon entering the meeting.
- I put a lot of time and effort in preparing for the planning meeting (approx 40-50hrs) and only one of the items I took in was taken by The Planner to be looked over at a later stage.
- I felt the Planner assessed my daughters competencies on the spot with trivial questions based on my opinion, from which she made her own assumptions.
- I was only allowed to choose 3 or 4 of the most important goals from my list for our daughter, as if the rest weren't important enough to be considered.
- I felt it was subjective, not factual, or based on the many medical reports I had provided The Planner with prior to the meeting
- The planner was rude, impersonal and like talking to a machine. I felt like I was being sold insurance- her response to this statement was that I wasn't entirely wrong, that this was to insure Australia's sustainability.
- I was initially denied an outline of what my daughter would receive if she became a participant of the scheme because it would be a waste of time and resources to create a plan if we weren't going to proceed. To me it's madness to commit to something that you have no information or idea about, particularly when it's something as important as my daughters future and wellbeing
- I felt I was being threatened to join the scheme- I was told that if we withdrew my daughter from the scheme that even if her circumstances didn't change they couldn't guarantee her acceptance back in to the scheme in the future.

- We were also told that BetterStart would be ending soon (but The Planner would not inform me of a date upon my requests) however upon my own investigation to FACHSIA I was advised that in fact the expiration date for my daughters funding still stood at 5/3/2019.
- 'Reasonable and Necessary' is something The Planner repeated constantly. She also referred to literature that "more therapy is not beneficial". I was not provided with any of the literature that she constantly referred to, until I formally requested it via an 'Agenda' I compiled after the fact. The research for recommended practice that the Planner referred to ended up being a number of outdated articles (as early as 1997 and 1988).
- Upon challenging "too much" therapy I was met with no set number of hours being "too much", that it was in fact at the discretion of the planner to determine how much was "reasonable and necessary".
- I feel NDIS staff have been misleading and deceitful in telling me on a number of occasions that because the scheme was in effect that no organisations would be taking new clients and not to bother approaching them for support (incontinence aids at disabilitySA and all services through Novita), which I found out to be untrue after a member on the board of Novita ensured me that this was not the case.
- I was advised at the Planning meeting that Novita would refuse to assist my daughter until she was a Participant of the scheme.
- After contacting Novita despite The Planners claim Novita felt it was irresponsible for my daughters development to be restricted for possibly weeks or months while the Plan was implemented and they insisted we engage them immediately- their visits commenced that same week due to her high need for support.
- CanDo4Kids who we have accessed regularly for our daughter since birth advised us that they would no longer be able to provide early intervention to her if we remained under BetterStart funding
- It is true that my daughter would have run out of money with her current BetterStart funding
- So in fact she is better off financially being a participant of the scheme. However it was brought to my attention at a hospital appointment during the planning process that once my daughter became a participant that she would instantly lose access to all Allied Health Services at Women's and Children's Hospital, which she was accessing frequently

and for free. It was for this reason that I contacted Novita against the NDIS' claim and engaged them to start working with our daughter immediately.

- We sought their advice on her condition, development and future and committed to an intensive regime. This regime was also endorsed by the Neuro Developmental Physio at WCH. I have reports from many specialists including Physios, OT, Speech Pathologists, Orientation and Mobility Instructors, Paediatrician and Neurologist supporting the input that my daughter requires in order to reach her fullest potential.
- My daughters Planner (a physio herself) advised me that I must “prioritise” the funding package she has been allocated. I perceive this instead as deciding what basic life skills I can't afford to teach my daughter because not enough funding has been made available. That is a heartbreaking thing to have to do.
- I left the meeting in tears because I felt that the entire schemes intent is to cut as much funding as possible, to save the country money. The planner was impossible to negotiate with and repeated the same versed responses over and over again, and referred to a document that demonstrated that “more therapy is not beneficial”, as a reasoning as to why my daughter would not likely receive/be able to continue with the same therapeutic regime she accessed at the time
- Allied Health services were not services we had to pay for previously with her BetterStart funding, however they are services we now cannot access at the frequency we were prior to being participants of the scheme because adequate funding has not been provided to do so. The Planners response to this was that this was a policy of the hospital, not the NDIS.
- We requested a repeat Planning meeting in-home. Again this was met with encouragement to be at the St Marys office but we insisted. We had also engaged an Advocate by this point who would be present at the meeting also.
- Following the initial Planning Meeting I made many phone calls to get advice and to give feedback on my experience. The issue we faced was that I had been told to be prepared not to receive funding for anything in addition to my daughters in-home Orientation and Mobility commitments (this excluded weekly Hydro Mobility, weekly Physio, weekly OT and fortnightly Speech Pathology and Communication).

- I was not able to access a proposed plan, and therefore I had nothing but words to dispute at this point in time. The situation I faced was to commit to a Plan with potentially less funding/services than was required, before being able to dispute it to get it back again.
- It is not OK to tell me to put my daughter in Child Care, as an alternative to me asking for help within the home.
- It is not OK to tell me to ask my friends to babysit Juno, or my parents to help for a 4th day per week on top of both working full time.
- It is not OK to tell me “not to rely on others to do everything for my daughter” and that I must adapt how I teach her instead, in response to me crying about how I don’t even know how to teach her basic things like what shapes are, or a dog, or how to talk and walk when I pleaded for Physio, OT, Speech and O&M to be in-home and to continue.

Resolution/Help

- I approached Tony Piccolo on 1/2/14 at a community event to raise my concerns. He was disinterested but assured me he would call me back before the following Friday. I received no contact despite making a call to his office requesting a call back and a message on his facebook page.
- I was however called by Karen Zollo on 17/2/14 from the NDIS North regarding my 'complaint'. Tony had taken it upon himself to complain on my behalf about our issues. I declined her passing the information on to our local office on my behalf.
- I called Tonys office again that same day and he was unable to speak with me however Rachel passed the information on to his ministerial office.
- Later that afternoon I received a call from Yvette from the Ministerial Liaison for Disability who after lengthy explanation understood my situation. She apologised on behalf of the minister and the office and assured me that she would find out whatever she could and get back to me. She affirmed that I wanted to let the ministers know the serious issues we were facing, that we weren't provided with anything in writing and were about to run out of funding. I never heard from her again. (82260322).
- On 17/3/14 Cosi Costa called me, after a friend of mine told him of the issues we were facing. He assured me he would pass my details to a David? (someone) at a Federal level to see what he could do. Again, I heard nothing back.

Assessment

- If I had not had the advice from an advocate and family involved in similar fields, I would not have known to question whether we are rural (which after persisting repeated times after researching our locality in relation to the CBD and mentioning our previous address was considered so and we're a kilometre further out, resulted in us being classified as Rural and in turn receiving an additional amount for travel). If I had not read the criteria for incontinence medical conditions I would not have known to argue persistently that my daughter requires nappies (which are now included in her plan). Information is not being given out freely- unless the right questions are asked and asked again and again, you won't get what you're entitled to.
- If we had not insisted on being made aware of what my daughter would be entitled to as a participant of the scheme we would not have been supplied a Draft Plan at the repeat planning meeting on 28/2/14.
- The Planner had no understanding or comprehension of any of the conditions and syndromes our daughter has yet she is able to decide what level of funding she will receive.
- In my daughters Plan the Planner refers to details from reports dated 2 years ago to support the rejection of additional funding, despite recent reports supporting more items and services are recommended.
- My daughter was declined funding for many things that we felt are reasonable and necessary however the Planner has decided otherwise. A bath for our house was declined because we have a younger child who would benefit from the bath and as a result it would not be funded, despite the fact our daughter is 26 months old and cannot yet stand so we drive her to be bathed at her grandparents, a 44km round trip (or put her at the base of a shower to be washed with a flannel without water to sit in). An iPad was declined, despite her OT, Physio and Speech Pathologists all using them with my daughter during their therapy sessions, because we have a light table that can provide the same experience. A Braille labeller was declined because it was deemed unnecessary until school age for her to be exposed to Braille, despite being legally blind and therefore is unable to read text.

Feedback

- It is a waste of my time that I cannot directly contact my daughters Planner- we are denied a direct phone number and email and instead are required to call the St Mary's branch and leave a message for her to return the call, or send an email to a generic address and hope that the admin direct it to The Planner. Then we wait for a response, which I more often than not miss because I'm called back at obscure times when it is no longer convenient for me to answer the phone. I then have to repeat the process again!
- I worry about the people who don't realise they can challenge the process.
- I worry about the people who don't know what questions to ask and how to ask them.
- I worry about the people who don't know about Advocacy services.
- I worry about the parents who's disabled children have far higher needs than my daughters, although they are both in the same 'high' bracket of funding- if we can't make it last for a full year of therapy then what will they do?
- I am not yet sure whether I will be disputing the Plan that has been put in place for my daughter as I'm sure if anyone is going to get more funding that there are more people than us with higher needs and I have run out of energy, time and motivation. It has broken me mentally. I will however be providing feedback by means of this committee and the formal feedback avenue available on the NDIS website.
- I'd like to have seen some of the \$34,000,000 spent on rebranding the scheme, or the \$450,000 in salary to retired prime ministers, be put back in to our most vulnerable. Disability is not the area from which funding should be slashed. I feel that the scheme is a way to monopolise the entire sector, take funding and control away from all the little organisations and cut costs. It's not about helping people at all. It's an absolute disgrace.

Advocate

- Although all of the NDIS literature mentions 'advocacy', there is not in fact anywhere that I could find the details of any advocacy agencies. It was only by chance, online, that someone gave me the details of where I could find one to assist us. Advocacy in the literature was used loosely as the person who advocates for the participant, rather than a professional who is skilled in the area and is free of charge, funded by the commonwealth and available to anyone who needs assistance to advocate for themselves or their dependant. I felt this to be misleading and lacking transparency.
- The aid of an Advocate has been invaluable- in her I have knowledge of the industry, advice, information, support and witness to every action and conversation. Everyone should have an advocate by means of a professional through organisations such as Family Advocacy Inc.

Funding

- I feel the funding structure is not individualised, tailored to the individual or flexible as was promised.
- It is unreasonable to discount numerous medical professional's reports and recommendations for what a child needs in order to reach their fullest potential. This is not me asking for an unreasonable amount of money for my own personal gain- I do not enjoy or wish to spend an hour a day, 3 times a week, in therapy however this is what my daughter needs. It should not be denied because I cannot afford it, or rather "prioritise" the limited funding the NDIS has deemed 'reasonable and necessary'.
- It is neither individualised nor flexible to categorise people in to 3 brackets; low, medium and high, and let that determine the amount of money they are entitled to.
- It is not OK to tell the mother of a disabled infant to "prioritise" the services he/she can receive, because not enough money is being provided to cover even the basic necessities.
- It is not OK to limit \$16,000 as the highest amount of funding available. I am glad my daughters needs have been recognised as 'high' but I am seriously concerned about the other people I have met recently who are also 'high' needs but with very obviously greater level of needs, care, time, energy and effort that even my daughter is. It's not a fair or equitable funding system.

Appealing

I am unsure yet whether I will appeal my daughter's Plan. The emotional toll that it has taken to fight as hard as has been required of me to get to this point makes me question whether it would be worth it. I am giving feedback both at committees, forums and formally via the NDIS website in principle. I am so very Thankful to have anything at all- without the scheme my daughter would have been without funding very soon. However the scheme set out grand aims and promises that in our case certainly have not been delivered. It is because of this that I am fighting- I fight for us and for all of the other families who haven't got a voice. I support lots of families who are currently in the planning process or about to enter in to it with my feedback and experience.

My Suggestions

Had the NDIA marketed the scheme along the lines of “We’re in a deficit and can’t afford to give everyone what they need. We know it won’t be enough. All the country can afford is to categorise you in to three brackets, which will determine what amount of funding you receive. It won’t cover all of your costs but it’s all we can give at this point in time”, I think there would have been far less backlash. From my experience of speaking to 20 or so families in the NDIS, only the people who have very low needs or a mild developmental delay (1 family only) who are happy with their Plan. It’s the people who need it most who are struggling to secure funding that adequately cover’s their associated medical and therapeutic costs.

It would have been believable too had there not been such outrageous amounts of money used on surveys and name changes and associated expenses in the first instance.

I also think that Planning meetings should happen in front of a panel, rather than an individual. This would help reduce many of the discrepancies echoed at the committee hearing.