

I would like to thank the Standing Committee on Health, Ageing and Social Services for the opportunity to make a submission to the inquiry. I would request the opportunity for me and my husband to address the Standing Committee when hearings are held.

Introduction

My experience since our first plan in 2015 is the following:

1. For each of the plans 2015/16, 2016/2017, 2017/2018 and now 2018/2019, the planning process was highly stressful and has resulted in a degradation of my health and wellbeing. My carer partner considers the process onerous and detrimental to both my health and his.
2. The planning and implementation process seems to revolve around one "Primary Condition" and has difficulty dealing with people, such as me, with multiple complex chronic lifelong psycho-social, neurodegenerative and degenerative muscular skeletal conditions. I was advised during my first plan I would be put in a distinct psycho-social NDIS team. I asked, "How will my equally significant disabilities be managed, for example, Parkinsons, which also crosses this boundary". There was silence from the NDIS planner.
3. Most of my health professionals have little experience or understanding of what is required by the NDIS and have not received advice from the NDIS on the requirements and acceptable NDIS terminology.
4. Specific training for support staff to assist people with specific conditions, e.g. psycho-social conditions, appears to be not funded by the NDIA.
5. The planning process does not allow for any interaction with the NDIA delegate during the approval process and results in the delivery of a "surprise" plan. We have not seen any draft plans since 2015/2016. This appears to be inconsistent with other states in Australia.
6. Since 2017, a third party has become involved in the planning process, the Local Area Coordinator (Feros Care in the ACT). This has resulted in further isolation of the NDIA delegate from me, the participant.
7. There appears to be no Records Management System that can be used by the NDIA in an effective way to keep track of who I am, what my disabilities are, my goals, to track my progress against these goals, submitted "Impact Statements" to review outcomes, to assist in the planning process and alleviate the stress of each plan review.
8. I must re-explain my conditions and disabilities to each of the assigned NDIA planners, now Feros Care, for every plan review.
9. There is no consistency of planning outcomes from one plan to the next, even though my underlying disabilities and conditions have not changed and there has been no change in my goals. My first two plans had varying levels of Support Co-ordination and my last two plans had no Support Co-ordination funding. This is contrary to submissions made to the Productive Commission, at a national level, by national peak bodies representing at least two of my NDIS recognised disabilities, Parkinson's and Psycho-social. The ACT does not appear to have personnel trained to provide "Complex Support Co-ordination".
10. Communication with other NDIS participants with similar conditions to mine show that there appears to be no consistency of outcomes from one participant to the next.
11. Communication with the NDIS has been poor. Correspondence has not been answered and explanations of outcomes not provided.
12. The NDIS has had some positive outcomes. My activities, particularly those associated with capacity building, have helped to mitigate some of the effects of my disabilities. The plans

have helped in my social interaction, given me more confidence and increased my sense of independence.

Questions

1. Why aren't the letters submitted by my professional medical team and reviewed by the NDIS, which state what support I require and what impact the conditions have on me enough? Why am I asked for empirical justification? Why do I have to write down how my disabilities impact on my day to day life when the NDIS is in receipt of formal professional medical advice on me?
2. Why do I need to explain my conditions and my goals every 12month when the NDIA knows that my conditions can only get worse and my goals not change? Why can't we have an indefinite duration for the plan subject to change in conditions?
3. Why, seemingly, doesn't the NDIA look at my history and past plans when deciding on the new plan?
4. Why aren't the national support organisations catering for a large demographic of the population funded to provide information to the NDIS on the conditions they look after? For example, in my case, Parkinson's, which has the second highest number of people impacted by a degenerative, neurological disease in this country, after Dementia.

It would be beneficial for the individual if the NDIA Planner had a full understanding of the individual's disabilities and the empirical based range of treatments and equipment recommended for the condition. This would make it less onerous on the individual and on the NDIA.

5. Why is it necessary for us to have to use a third party (Feros Care) to interface with the NDIS every year when this leads to communication issues?
6. Why can't we have an assigned planner within the NDIA who is able to build a relationship with me and help me to negotiate the NDIS requirements?

My Initial Experience with NDIS Planning Process

Doing my Personal Research on the Scheme

My interest with the NDIA was triggered by attending the "Control and Choice" Expo at EPIC in May/June of 2014, which was a precursor to the launch of the NDIS ACT in July 2014. I registered my name with a few Providers at the Expo and have since been the recipient of regular ACT NDIS news via, "Catholic Care" and Multiple Sclerosis Limited (MSL). I wrote an article in June 2014 for the Parkinson's ACT Newsletter. At that stage I found the NDIS national website, personally, very incoherent and had difficulty finding information. The ACT website was much easier to follow. Much of the background information for the article was provided by MSL and the ACT website. Note: For the first time in months, I went back to the national website today and found many of the links to the ACT did not work.

Communication between the NDIS and potential NDIS Individuals

My first formal contact with the NDIS was filling in my "Access Checker" on the 29/5/14. I received no communication from the NDIS and all communication with the NDIA was initiated by me until I received a phone call approximately five days after I had lodged my "Evidence of Disability Form" and "Access Request Form". A member of the NDIA team said I could lodge these forms now. Catholic Care and the MSL had provided the vital information on the ACT rollout over the past year.

The forms were hand delivered to my home the same day, the 9th October 2014. I had an appointment with my Neurologist in November 2014 and asked for his support in my NDIS application. He told me he was not familiar with how the NDIS worked, nor did the rest of my medical team. My Neurologist recommended for my Parkinson's balance issues I do the "PD Warrior" Programme which was based in Sydney, but not available in Canberra. The first formal and only workshop, my husband and I attended, marketed by Catholic Care, was the NDIA Pre Planning Workshop, 12th November 2014.

Confusion when there is more than one "Primary Condition"

The "Evidence of Disability Form", under the heading "Diagnosis", asked the doctor filling in the form to list the "Primary Condition". This caused personal confusion as I had more than one prime disability or condition. I contacted the NDIS ACT and was told each of my medical team would need to fill in a separate "Evidence of Disability" form, each eleven pages. This meant the initial six, eventually eight, medical professionals, would need to do all this paper work, all working in isolation of one another. The person I dealt with, asked for the names and addresses of each of the members of my medical team so they could send them each a "Form". I had concerns about the burden placed on so many professionals and how cohesive the information would be for the NDIS ACT team to read.

In December I met with my GP and she agreed, the most logical approach would be for her to collate supporting letters from my medical team and submit just one Form. She gave me the task of going back and trying to get someone in the NDIS to agree with this approach. Eventually I received a phone call from a very obliging and logical, senior NDIS delegate who conferred, the previous advice I had been given was onerous. He said no forms from NDIS ACT had been sent out to the six medical professionals as yet. He wanted to know how long I had my GP (since 1987) and advised it would be best if the GP took on the role of collation of diagnoses of the six medical specialists roles I listed with him and how they impacted on my life.

Keeping everyone involved in the "Application Process" informed.

The process of having just one form per potential individual agreed to by the NDIS, educating my medical team about the NDIS and receiving my final "Form" filled in by my GP, started on the 10th of

November 2014 and was completed near the end of March, 2015. My biggest concern was each time I met with one of my medical team, I was met with the same response: "I do not know anything about the NDIS and what is expected of me". My final letter of support from one of my prime medical team members, did not arrive until the 16th of March 2015.

This process alone, took, four and a half months. I felt very pressured into understanding the workings of the NDIA. It is very important your future individuals have plenty of warning and maybe a letter from the NDIA to give to their doctors, explaining what the NDIA requires in supporting evidence from medical professionals.

Fortunately, I rang the ACT Office on the 31st March 2015, before submitting both of these forms on the 1st of April 2015. I was told the "Access Request Form" I had received on the 9th of October 2014 was outdated and the new form was emailed out to me on the same day. I redid the form submitting a few days later. I received a letter on the 6th of May stating my "Access Request" was successful and came into effect on the 5th of May 2015. My planning meeting was set for the 3rd of June at the NDIS office.

Being across the support you can receive and your options in the Pre-planning Phase.

With advice from MSL, Catholic Care and ACT Disability and Aged Care, Advocacy, I applied for a "NDIS Community Participation Grant" which could provide me with financial assistance for a "Life Coach", in the pre and post planning phase (I was successful in this application.); changed the venue for my first meeting from the NDIS site to my home where I my anxiety levels would not be so high; arranged for an Advocate to be present at this meeting and also an extension of two weeks before my initial meeting.

The Writing of the Plan

Since I submitted my "Evidence of Disability Form" I have felt overwhelmed by what the NDIS was asking me to provide in my "Participation Statement". When I received my letter saying I was a successful applicant, attached was a new form. I found out too late, I had been filling in the "old" Participation Statement.

I felt the pressure of justifying every item I asked for and having no comprehension of what was a "reasonable expense" or budget to cover my costs. The NDIA, in all its information talked about the need to have "Life Goals" in all appropriate areas of your life and making sure you were also an active individual of the community and had a social life. I was torn between writing down what my real goals were and just asking for a few items. There is no benchmark to work with.

One example I grappled with was the high cost of transport, highlighted as I added to the spreadsheet, the list of all my medical team, their addresses, the return visit length and time and the estimated quantity for the year. I found the whole process degrading as every time I leave my home I had to explain to the government where I was going and why. I had lost my licence, due to my disabilities, in March 2015. It was pointless applying for a "Mobility Allowance", as it coincided with my application to enter the NDIS. My husband has been my chauffeur since he retired in March this year. I could see the impact this was having on him and our relationship. I contacted the Human Rights Commission and asked if they could help me find someone to talk to in the NDIS, primarily, around transport. The "Mobility Allowance", now under the NDIS, did not cover the costs of seeing my extended medical team and there will be nothing left for a social life. Again, I was put in contact with a senior NDIS delegate, who suggested my husband write a "Carer Impact Statement" to this I added my own "Transport Impact Statement".

My husband put together spreadsheets and tried to work out what codes were required for each item; if the item, we felt was expensive, provide, as advised in the "Pre Planning Workshop", empirical based evidence for what I was asking for.

I feel the NDIS is making the assumption the average lay person with a disability has a tertiary based education, has access to this information and can put in the most appropriate research papers. We finally met with the "Life Coach" we had engaged who demystified much of how the NDIS worked and I was given advice on further assessments I needed to organise, then went through the process of chasing up quotes, reports and more evidence.

The plan went through a number of drafts with the final plan approved 22 July 2015 with intended review by 21 July 2016

I was hospitalised on 7th October, 2015 for 4 weeks suffering from stress, anxiety.

We engaged a number of registered service providers to assist in plan implementation however we found none that could provide the level of personal support and understanding that we required and, as a result of hospitalisation, poor health and difficulties in implementation, we underspent our allocated funding, that is, except for transport.

Subsequent Plans

2016-2017

The 2016-17 plan occurred while I was very unwell and was spending considerable time in hospital.

The NDIA was also in the process of changing its portal. Codes for expense were also changed.

We provided the NDIA planner assigned to us all documentation from the previous year, including my Goals. As a result, the NDIA planner assigned was able to negotiate on our behalf an improved plan with increased funding.

The Plan started 04 August 2016 with a review by 03 August 2017.

We also received some funding for some internal house modifications involving handrails and modifications to stairs. We were able, eventually, to use this funding.

One of the funding categories requested was support coordination.

I wanted to use this to help alleviate the stress of sourcing my own supports and to help me manage my interaction with my health professionals. This was unsuccessful as the service providers were not equipped to provide the support I required.

During this time, we discovered new Web based service providers Hireup and Better Caring. We interviewed and hired our own support workers using these services. These were considerably more successful than the traditional Service Providers. We also employed contractors for day to day support, such as cleaning and maintenance.

The disadvantage is that I spend a significant amount of time proving my own support coordination.

2017-2018

Around June 2017 we received a phone call from Feros Care saying that they were the Local Area Coordinator for the ACT and would assist in developing our plan for 2017-2018.

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We were concerned that all my private details had been passed to a third party, Feros Care, without my knowledge and that they could access all my records on the NDIA systems. I wrote to the NDIA expressing those concerns and received no response.

We agreed to meet with Feros Care because we seemed to have no other option. We provided the planner with all copies of our previous correspondence and plans plus detailed costings on our future needs.

The plan was approved 1 Sep 2017 with a review date of May 2018, with nearly all our requests acknowledged and approved.

We had asked for some additional house modifications however they were not included.

We continued to use the services of Hireup and Better caring with remarkable success. We had plans for various Capacity Building programs and home stay programs so that my carer husband could have some respite.

Not long after the plan was approved we received advice from Feros Care that our planner had resigned, and we had a new planner assigned. We met with this planner, acknowledged how we were satisfied with our new plan, however we still needed our house modifications, consisting of a ramp and handrails.

This new planner said she thought that the omission of the house modifications from the plan was an error and that she would get the house modifications added. This would necessitate the issuing of a new plan.

This person submitted a request to the NDIA and then advised that she would no longer be our planner and another Feros Care employee would be our new planner

2018-2019

We were advised by our latest planner on about 27th February that our new plan had been approved and that it included an item for house modifications, however with \$0.00 assigned. We explained that all quotes had been uploaded with all necessary supporting documentation and that there should be a dollar amount.

Upon reviewing the plan, we then discovered that over 80% of the funding that we had just received in September 2017 had been removed from the plan. This has had significant impact on my goals, my support workers, my carer husband and my health.

The new plan is 60% of what was received in 2015/16, 34% of what was received 2016/17, and 20% of what was received only five and half months earlier for 2017/2018.

Transport alone has been reduced to 48% of that received in 2015/16.

No explanation has been provided either by Feros Care or by the NDIS.

Feros Care have not been in contact since the end of February.

We have been to the local Braddon NDIA office and made representation to a senior NDIS planner and are waiting upon an outcome.

Psychosocial Disability impact of the NDIS and role of ACT based NDIS and traditional Service Providers

The NDIS process has traumatised me and has led to chronic depression, poor health and the need for lengthy hospital admissions.

NDIS Plan 1: 22nd July 2015-21st July 2016 + extension to 31st August 2016

Hospital Admission – 7th October to 6th November 2015(1 month)

NDIS Plan 2: 1st September 2016 to the 31st August 2017

Hospital Admission –6th July to the 5th September 2016

This NDIS plan was implemented without sighting or sign off while the NDIS was aware I was in hospital.

NDIS Plan 3: 1st September 2017to 31st August 2019

Hospital Admission -14th to 25th September

NDIS Plan 4: 22nd February 2018 to current

Letter hand delivered to the NDIS 5th March 2018

The NDIS in the ACT along with ACT based Psychosocial Service Providers and mainstream ACT Health providers were lost with the introduction of the NDIS.

- My psychosocial needs were completely ignored in my first plan written by the NDIS.
- Not one of the groups listed above in the ACT had/have the skill set to comprehend the co-morbidities of:
 - Lifelong serious psycho social disabilities; and
 - Psychosocial disabilities associated with a neurodegenerative disability.
- I was promised support and signed an agreement with a Psychosocial ACT based group after waiting two years to get into the program and two months later was told now I'm under the NDIS I no longer will get assistance via ACT Health or this group.

Many traditional registered ACT Service Providers have either said they have no staff available after an initial meeting, they need to take my case to their board, demand my medical information without signing any formal privacy agreement or Misinterpret the information I have provided them in writing a scope of work due to ignorance or add additional health conditions based on their nonprofessional assessment of me.

- I was continuously shuffled from one ACT Service Provider to another when I engaged an ACT advocacy group and later a specific Psychosocial Support co-ordination group to find someone to manage my NDIS plans.

These groups decided to take on Support Co-ordination for me with unskilled staff.

The first question I was asked when we were negotiating terms was: "What would you like me to do?"

My privacy and rights as an individual are violated by the NDIS and ACT based Service Providers.

ACT NDIS representatives do not manage my privacy around my personal medical and disability information. The NDIS do not give me any personal information around how they protect my privacy. The NDIS gave all my confidential information to a company called Feros Care without asking my permission. The NDIS has not responded to messages my husband and I have sent them asking who Feros Care is and why have they got my confidential information.

The NDIS have not trained or audited their staff, contractors who represent them or registered providers to provide formal identification when meeting me for the first time.

I have previously formally written to the NDIS about breaches of my privacy by a Service Provider(SP) in February 2016. I met with a representative of the NDIS Braddon, ACT on the 3rd March 2016. The NDIS would not manage the seriousness of this matter. I was advised current SP not good fit, seek support from an advocate agency for privacy breaches. I engaged the services of an Advocacy agency which involved having to write a report and have my case be put before their board, before taking me on in March 2016.

Response after 2 months around privacy breaches:

"I have given some further thought to moving forward with your complaint against XXX regarding your medical files. I have included below links that provide information about Office of the Australian Information Commissioner.... This would first require then to accept undertaking your complaint, it is not clear what criteria they work within. Please take time to review the information I have provided and then may be useful to discuss how you feel about it.

I rang the Office of Information Commission and they told me I had a strong case."

Impact on my disabilities:

- I am too traumatised to undertake any process with the NDIS by myself.
- I have lost trust in the NDIS.
- When I set up meetings with Registered Service Providers under the NDIS I need to constantly tell them my private health status.
- My Neurodegenerative Obsessive-Compulsive behaviour and Psychosocial disabilities are in constant high alert
- I need to waste hours of my time reading, interpreting and explaining the NDIS to my Medical professional disability team.
- I am constantly trying to find out who is responsible for looking after me which puts me in trauma
- My health is severely impacted by the confused Responses I receive.

Impact on my disabilities:

I am continuously being traumatised by the need to retell my personal disability information to the NDIS and by verbal promises which have never been implemented

Since engaging with the NDIS I am continuously being required to justify my disabilities. I have never sighted a summary of my disability needs and I am continuously asked to define my goals etc in plan reviews

To put in place funding given to me by the NDIS I need to continuously retell strangers about my disabilities.

I have become very dependent on my husband's support and finding NDIS registered "Support Co-ordination" and sourcing general activities under my plan has added a significant burden to our lives. The introduction of the NDIS has meant I can no longer give quality time to my health and wellness, cannot pursue my personal goals and am constantly being interviewed or are the recipient of reports

from registered providers who are not across me as a person. I have become more socially isolated since the introduction of the NDIS, feel degraded by having to give out personal details to strangers.

Due to multiple experiences, I have had I have become extremely vulnerable in the individual care of untrained workers who don't share my goals, with their only requirement, a "Police and Working with Vulnerable People" check,

- are not supervised in their working practice,
- including, for example, first time experience of respite care management by an intimidating provider who threatened to tear up my contract.
- Agencies who have lost financial backing in the NDIS transition process who have promised and then taken support away from me.

Support Workers do not show up. Service Providers do not brief their employees on their roles outlined in our Service Agreements which mean I spend the time explaining their job.

Send two employees to do a job in half the time which exhausts me and gives me more stress.

Companies who have been traditional suppliers of Social Support, lack overall management of their employees, leaving for example up to us, the responsibility of timesheets for accounting and notification to them if their employees don't show for a shift.

They seem to need to dictate set times of day etc; which I need to accommodate, to meet their needs.

Traditional registered Service Providers have either said they have no staff available after an initial meeting, or decided without collaboration or trial, the supply of unsupervised, untrained support ranging from very young staff, who decided their role was to train me to be more independent in carrying out household tasks such as cooking; support workers who drove large four wheel drives, which were difficult for me to access, to those who had some tertiary education, who tried to manage my formal interaction with medical specialists, while providing social support to undertake appointments.

In one instance, a Support Worker became unstable due to personal problems, was rude to a professional volunteer at my prime social outlet, "Art Therapy" and left me at an activity without a means of getting home.

This was further complicated by the ongoing inability to use a mobile phone, never fully comprehended or addressed by repeated interactions with NDIS registered Assistive Technology specialists who would come down from Sydney.

- **We don't have this skill set in the ACT**

Examples:

6-7 May 2016: Two invitations via email to participate in NDIS Surveys giving feedback on ACT trial. Both surveys gave option for interview in my home. I agreed to both and asked for interview in my home, no follow up by those involved in survey.

May 2016: Contacted NDIS advising change of health status of fulltime Carer husband. Unexplained brain seizure of approximately four hours, resulting in need to call ambulance and my delivery of CPR. My husband was without a car licence until November 2016. Advised by my NDIS Plan Manager I would be having a formal plan review soon and taxi allowance increased.

Not implemented.

May 2017 NDIS Invitation: Participant and Provider experience workshop with new NDIS CEO - Sydney 10 May.

No consideration of my personal needs, and no response on my stated feedback to NDIS personnel. The NDIS sent out, a form, asking about my requirements for wheel chair access, sight, hearing and

dietary requirements. The NDIS had, as yet, not designed an “all inclusive” disability requirement form, for example catering to psycho-social and neurodegenerative needs.

May – June 2016: Continuous reassurance there would be additional support for me and I would be put in a “distinct psychosocial” NDIS team who would work closely with me. Not implemented.

July 11, 2017: Phone call by me to NDIS main switch board; verbal guarantee an email would be sent to my local NDIS Braddon office, with questions dictated by me asking who Feros Care is, why have they got my personal information and why didn’t the NDIS tell me they were engaging them. Email by my husband along same lines. No response from NDIS Braddon to date.

July 10 and 17 2017: Feros Care left messages on my husband’s mobile and our landline asking to speak to my husband about my plan review. They were not briefed by the NDIS correctly.

Neither message asked for contact with me, the NDIS plan holder who has the mental capacity to sign a NDIS Plan.

Meeting with Senior ACT NDIS Planner 5th March 2018 after issue of 4th Plan

Comment: After reading my repeated request to not have to go through the trauma of annual reviews, was told they had been discussing locally the need to handle people with psychosocial disabilities differently.

Availability & Quality of Services for people with a disability in the ACT

The NDIS and the Australian and ACT public and private health systems have not defined clearly who is responsible for what functions in disability management.

I have found it impossible to fully define who is responsible for day to day management of my conditions which are a direct impact of my NDIS recognised disabilities:

- a. Emergency and continuous, regular ongoing specialised oral health management and related expenditure on items to manage further deterioration.
- b. Ophthalmology and issuing of prescription glasses direct impact of a neuro degenerative NDIS recognised disability.
- c. Daily usage of over the counter topical creams to manage skin conditions, a direct impact of a disability.
- d. Complex ongoing daily medication management and related expenses, such as Webster Packs and employment of Support Workers trained and qualified to monitor and keep these records up to date.
- e. Requirement of a Complex Case Co-ordinator for Advocacy and medical support around ACT hospital admissions, appointments with GPs and Specialists within and outside the ACT.
 - a. This skill set is not easily available within the ACT. There is a skill gap.
- f. Division of responsibilities between an ACT GP and the NDIS around “Health Complex Chronic Care Plans”
- g. Expenses incurred not covered by ACT Health, when travelling interstate for appointments with highly qualified specialists not available in certain fields within the ACT.
- h. Funding gap incurred by NDIS participants using Medicare when requesting detailed documentation for NDIS requirements or direct costings for health professionals not covered by Medicare.
- i. Funding gap between the Federal Government’s annual Carer’s Allowance and the amount of day to day administration required by Carer’s to Self-Manage a participant’s annual NDIS Plan.
 - a. **Note: This is very relevant to the ACT as on a pro-rata basis the ACT has the highest percentage of NDIS participants who self-manage their plans.**

Role of National, ACT Advocacy and ACT specific disability groups

The implementation of the NDIS within the ACT was met by most national and ACT specific groups in an unprepared manner.

- There was much effort put into trying to procure ongoing funding for their services prior and during the NDIS trial in the ACT and after the formal national implementation
- Many groups suddenly saw the need to provide documentation at a national federal level to various enquires the NDIS and independent Federal Government departments undertook.
- The introduction of the “Information Linkages and Capacity building(ILC)” caught many ACT specific disability groups off guard and submissions to the grant tender process was not carried through and groups lost funding and needed to go to the media for assistance with their cause, for example, SHOUT.

National and ACT disability groups lost focus on managing the needs of their individual funded members in the ACT who were struggling with trying to understand the NDIS.

I was confronted with national and ACT groups who:

- Took away all support for me because I was now an NDIS participant.
- Lack of advocacy and support for ongoing new plans after the NDIS trial phase was completed.
- Informed me they were advocating at a national level for specific support for me
 - which was not filtering down to the local ACT NDIS Planners.

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- The role of these groups became focussed on advocating nationally for specific disabilities with no value added to me or other individuals on their day to day renewal and management of their NDIS plans.
- I and my carer husband were left alone to advocate for our needs.

ACT Specific requirements under the NDIS

- Assistant Dog laws, training and breeders are required
- Introduction of “Mental Health First Aid’ training as mandatory requirement for NDIS Support Workers working with NDIS Psychosocial participants
- Formalised screening of suitability of people who have done Certificate 4 in mental health to work with NDIS participants. Comment from a Psychiatrist in the ACT:
 - *“Many of my clients have done the course”.*

National Standards for Disability Services

The framework for the National Standards for Disability Services promotes person-centred approaches and is based on principles related to Human Rights and Quality Management. My understanding is these standards were updated through major consultation with all parties involved in working with this updated version of the framework to be ready for the introduction of the NDIS within Australia.

If this "National Standards for Disability Services", document, Version 0.1, December 2013" is accepted and in place then:

1. Focus is kept on the person with disability as the primary partner - the National Standards are ultimately about people's quality of life and service experience.
2. The NDIS and registered NDIS Service Providers are now working within the framework outlined by this "National Standards for Disability Services". Below is an extract from the document:

"Six National Standards

There are six National Standards that apply to disability service providers.

1. **Rights:** The service promotes individual rights to freedom of expression, self-determination and decision-making and actively prevents abuse, harm, neglect and violence.
2. **Participation and Inclusion:** The service works with individuals and families, friends and carers to promote opportunities for meaningful participation and active inclusion in society.
3. **Individual Outcomes:** Services and supports are assessed, planned, delivered and reviewed to build on individual strengths and enable individuals to reach their goals.
4. **Feedback and Complaints:** Regular feedback is sought and used to inform individual and organisation-wide service reviews and improvement.
5. **Service Access:** The service manages access, commencement and leaving a service in a transparent, fair, equal and responsive way.
6. **Service Management:** The service has effective and accountable service management and leadership to maximise outcomes for individuals. "

The individual who becomes part of the NDIS scheme should benefit from these National Standards. For example:

- a. The NDIS advertise service providers who have adopted these standards and have been continuously successfully audited under the Quality Management process
- b. The individuals who are participating in the NDIS understands these standards
- c. There is in place, scope to allow the individual to be part of the Quality Management process and explain what this means and what the individual should expect in areas of service delivery by both the NDIS and Service Providers.
- d. Individuals are not confused with government (NDIS) and service provider interpretations of these standards and apply transparency across the whole disability sector. Examples of this include, but are not limited to:
 - i. The adoption of the agreed "National Standards" term "individual" by both the NDIS and Service Providers:

"Individual – the term 'individual' is used to describe the person who uses a service or support. This is primarily people with disability who use a service or support. The word 'individual' may also mean a family member or carer, for example, in the case of people using respite services. 'Individual' is used instead of words such as 'consumer', 'client', 'service user' or 'participant'.

- ii. Transparency in the process NDIS employees use to "accept" individuals into the NDIS scheme and manage ongoing plan renewals to avoid constant "disputes" of individuals around their plans.
 - This means individuals understand what documentation, word usage, etc is required by the NDIS to meet their goals and needs within a plan and on plan renewal or alteration.
 - Medical professionals who are supplying "letters of evidence" to support an individual's entry into the scheme have access to the guidelines used by the NDIS for accepting an individual and can frame their correspondence in accordance with these guidelines.
- iii. A functioning national NDIS national records system for maintenance and summary of everyone's current and previous plans, all medical letters of support and individual's impact statements. The current process means I need to provide copies of all previous documentation which an individual planner deems appropriate.