**Submission by Sarah Sutton, South Australia**

I work as a Forensic and Clinical Psychologist and have done so for the past 20 years. However, most of my knowledge of psychosocial disability is from being a sibling with two brothers who have had psychosocial disabilities for the past 30 years. Our family’s experiences drove my mother and me to become advocates because my brothers were not able to advocate for themselves. I am currently the SA carer representative on the National Mental Health Consumer and Carer Forum, I am also on the NDIA’s Independent Assessment Working Group and I have also recently been appointed to the NDIAs Intellectual Disability Reference Group. I also work part-time for Correctional Services in South Australia, assisting prisoners gain access to the NDIS.

I grew up in a house where one of my brothers was coward punched in an unprovoked assault at a party and sustained a broken jaw and an acquired brain injury. Only months later, my other brother became unwell and was diagnosed with Schizophrenia.

For most of the past 30 years, my brothers received very little paid disability support – my parents – who are now aged in their 70s - have provided, day in and day out, financial, social, emotional and practical support to my brothers. My parents have assisted with mobility issues – taking my brothers to various appointments and supporting them during appointments, they have assisted them communicate their needs, advocated on their behalf, taken them to community events, assisted them understand Centrelink documents, managed their finances, bought them a house to live in, maintained their households, and helped them look after their physical and mental health needs.

Thankfully, and only after a 30 year wait for adequate services, my brothers received their first NDIS packages in early 2019. Their applications were extensive, one was 70 pages long. Most of these assessments were medical reports, documenting their diagnoses and clinical symptoms. Their main NDIS goals have always been to live independently in their own homes, not with their parents, therefore the assessments did not really document their abilities to live successfully in the community - their functional capacity. After all, we had all been told many, many times by mental health services that they would NEVER be able to live independently.

Therefore, their initial 3month NDIS plans had approximately 10 hours of support per day of core hours, but more importantly, with additional funding in capacity building for further assessments and reports by a Developmental Educator. These two assessments - essentially independent assessments as she had not met my brothers prior to this - were conducted by a very experienced DE, who was recommended to us because of her experience with psychosocial disability, and she took many hours over several weeks meeting with family members, building our trust, meeting with support workers, however, only a small amount of time with my brothers assessing their needs. One of my brothers is mute and the other does not communicate much at all, so her assessments relied mostly on observations, collateral information and as I said, primarily through discussions with family members.

The information gained by the support workers during this assessment period was also vital in coming to the eventual conclusion that they required 24-hour care. The support workers are not all allied health professionals (some of them are), but most importantly, they are caring and non-judgemental and by spending so much time with them, they learned from my brothers what some of their goals were and what was not working and what could make things work better.

The support agency – SA Hope – are amazing and they also conducted Exploring Housing Assessments and completed the Supported Independent Living reports. Again, this took months, hours of discussions, meetings between the many stakeholders, emails, phone calls, planning meetings with the NDIA planner from the Complex Support Needs Branch. Eventually, these assessments resulted in an increase in my brothers support hours, first to 14 hours per day, and currently, two years later, they have 24 hour Supported Independent Living funding.

The importance of this information is that my brothers‘ circumstances HAVE NOT changed in the past two years, they have not entered a new life phase and their functional capacity has not changed (yet). If the proposed independent assessment policy was in place at that time in 2019, they would likely still be under their original plan of 10 hours of funding per day, which, to be truthful, would likely have resulted in the death of at least one of my brothers, as this would not have been sufficient compared to the 24 hour care that my parents provided prior to the NDIS. That thought is VERY, VERY scary.

My brothers have 24 hour funding because they do NEED it.

My brothers have great advocates - my family members – who know the system well and can navigate it, and we also know my brothers needs very well, and we are not afraid to speak up when things aren’t right. Our lived experience in conjunction with skilled, caring support workers and also professionals with experience in working in the psychosocial disability area who were funded to spend time getting to know my brothers and listening to lived experience of consumers and carers not just saved the lives of my brothers and my parents, but it has significantly improved the lives of my entire family!

**Therefore, I have devised a summary on how the NDIA can assist other consumers and carers to achieve NDIS packages that meet their disability needs, similar to my family situation. However, first I would like to address the claims made by the NDIA that the Independent Assessments are being introduced to promote equity and consistency, as these proposed changes will, in my opinion, NOT assist the NDIA create fair and consistent NDIS packages.**

**Consistency in decision making**

NDIA want consistency in reports, and less need for participants to seek reviews, and believe that by using the same tools for everyone that **consistency in decision making** will be achieved.

What does this actually mean?

Currently the staff within the National Access Team of the NDIA decide on eligibility, including functional incapacity, and I definitely agree that it would be preferable for allied health professionals to make these decisions, as I have witnessed first-hand the inconsistent decision making that takes place in the Access Team. For example, I even know of two identical twins, who have the same severity of disability and it affects their functioning to a similar degree, and still to this day, one has been found eligible for the NDIS and the other has not.

It’s my understanding that NDIA believe that many of the current assessments don’t take into account a person’s environment, their health and other factors, and that the same disability does not have the same impact on different people. However, a whole of person assessment, which the NDIA have stated they want, will NOT be possible when undertaken by a stranger particularly with little time. A whole of person assessment would consider whether a person lived in poverty, had stable housing, had something meaningful to do, had good physical and mental health – the social determinants of health and wellbeing – however this is not going to be achieved by a WHODAS, a Vineland or a CHIEF assessment completed by a stranger.

What if you lack insight into your capacity issues, you tell the independent assessor you are fine and don’t need help, and you have no family members or supports who can provide context and would otherwise provide information that you are not actually fine. This would result in the person continuing to live their isolated life, most likely dying from neglect, which is why statistics demonstrate a 25-year reduced life expectancy for this cohort of the population.

Any GOOD allied health professional knows that there is always the need for assessments to consider the person, their environment, their history, background reports, other collateral, and also the views of those who KNOW THE PERSON BEST!!! How will this be achieved by someone who has NEVER met the person or the family? There is even a case that was before the Administrative Appeals Tribunal Ray and NDIA (2020), which demonstrated that observations by a treating health professional who had a relationship with the person were more accurate than those of the Independent Assessor. A Productivity Commission document stated that independent assessments are needed to reduce **sympathy bias**. God forbid a health professional formed a therapeutic relationship with a client! This is outrageous!

Whilst it is good in theory that the independent assessor can go to your family, your usual support workers, your psychologist, your recovery coach, to gain their input, how are these disability providers going to be paid for their time, let alone if they are even available? It is likely that they will not have the time to provide the much-needed information to the independent assessor, nor will they work for free.

Of course, if you are already lucky enough to have an NDIS plan, and you need an independent assessment due to changes in your circumstances, all your NDIS funding would have already have been carefully allocated and it is likely you do not have a spare cent in your NDIS plan to pay workers to attend a meeting or spend time talking with an assessor. If you are not already in the scheme, who is going to pay these workers for their time?? The proposed solution does NOT solve these issues, as people cannot afford to pay for this out of their own money, they are likely on a Disability Support Pension.

Family members of those with disability also DO NOT have SPARE TIME up their sleeve. Carers of people with psychosocial disability are time-poor, work full or part-time, and are emotionally and physically drained. It is even more difficult when the carers are elderly parents. However, if they knew that a proper assessment would be conducted that would enable their loved one to receive the supports they need, they would make the time to talk to an assessor.

In addition, at what financial and emotional expense are these independent assessment strangers being employed? I argue that this will ruin and perhaps even end the lives of some people with a disability. In my mind, it is less of an emotional cost to request and endure a review, despite how painful and traumatic that can be, than losing your life!

Also, weirdly enough, **actual** human beings do not fit into boxes, and whilst the NDIA aims to use independent assessments as they are considered “disability-neutral” and can be used across all disability-types, specialised assessments are actually needed for each person depending on their unique needs.

In addition, in relation to the high number of review requests that have been cited by the NDIA as an issue – it appears that the solution of an independent assessment will not even be subject to a review! You cannot ask the Administrative Appeals Tribunal (AAT) to review your independent assessment. Therefore, there are currently a high number of reviews being sought, and this solution will definitely reduce the number of reviews, as they are NOT ALLOWED!!!

The only time you can ask for an updated independent assessment is when your functional capacity has changed. So if you don’t like the independent assessment, believe it does not account adequately for your needs, you are OUT of the NDIS!!! This is NOT a solution and it certainly is NOT choice and control, which is meant to be a fundamental tenet! It WILL result in deaths of people with a disability.

The solutions to these issues are that if these independent assessments go ahead, they need to be truly holistic, and they need to allow sufficient time to talk with the person and their family. Funding needs to be provided so that those who are working with the person can allocate adequate time and effort to contributing to the assessment. If a person with disability cannot articulate their own functional capacity, and/or their support needs, provide real choice and control so the person can fund an allied health professional of their choosing, who has specialist skills and experience in their particular disability, to undertake the assessment. Significant weighting needs to be given to the information provided by those who know the person the most, and the independent assessments need to be subject to the normal review processes. Also, people need significant assistance to understand the entire process. In order to provide fully informed consent, if a person does not have family or other supports, they need funded case managers or advocates. It would also be useful if the same assessor was provided each time a person needed an independent assessment.

**Independent assessments are free**

This appears to me to be the only real positive thing about independent assessments.

However, even this is a huge issue as the proposed independent assessment process is only fixing HALF of the issue – in order to meet access to the scheme, a person must prove that they have a disability, and then the second step is to demonstrate that it significantly affects their functional capacity. **The independent assessments only consider the second step, functional capacity.** The person will still need to pay for an assessment, and wait for an assessment, to determine whether they have a disability in the first place. If you have more than one disability, then that may involve multiple costs for multiple assessments, in order that you fit into some magical box named a primary disability. Therefore this is not fair, and it is definitely not equitable as those living in poverty will still be unfairly disadvantaged.

If the person does not have this evidence, the NDIA needs to provide choice and control so the person can fund an allied health professional of their choosing who is first and foremost caring, and secondly, has skills and experience working in the psychosocial disability area. Also, funding a consumer or carer with lived experience of psychosocial disability to provide expert oversight over each assessment would be advantageous and do NOT pay them a reduced wage like the Recovery Coaches model does!

**NDIA states that lengthy wait times will be rectified by IAs**

I seriously doubt that enough skilled and experienced OTs, psychologists, speech pathologists and physiotherapists will be procured through the tender process. These workers will not magically appear from nowhere. One way to reduce wait times is to widen the scope and allow participants choice and control to employ specific, skilled and experienced professionals that suit their particular needs - such as Developmental Educators, and of course this will vary for each person. However, as stated above, I also advocate for individuals with lived experience providing expert oversight over each assessment.

**Exemptions**

The delegate’s decision not to grant an exemption for an independent assessment will not be a reviewable decision.

Outside of exceptions, if an applicant chooses not to complete an independent assessment, NDIA will consider that the applicant has withdrawn their access request.

If you can’t have an independent assessment, it’s my understanding that **you** will need to give the NDIA information - so if you’re in prison and deemed a safety risk, you are homeless, or you are in hospital with psychosis and therefore you are quite unwell, you will need to ask for your own assessment and then pay for your own assessment? With money you don’t have as you are on a disability support pension? What if you are also illiterate? What if you don’t open or can’t read letters, or you don’t answer phone calls from private numbers because of social anxiety?

How will you even notify the NDIS that you can’t complete one of these assessments? In determining eligibility, the NDIA considers whether a person has substantially reduced functional capacity in communication and social interactions, and yet they expect you to reach out to the NDIA and ask for an exemption, even if you are in prison or in hospital in the midst of a mental health crisis! It makes no sense!

Who will complete your independent assessment if you are a Traditional Aboriginal person, a person who was born outside of Australia – where and who are these professionals with English as a second language going to magically appear from? And how valid are these assessments on people from all different cultures?

What about if you are in prison and have fallen through all the gaps, you may have a squillion different diagnoses but no evidence of your functional impairment. You have likely had many different assessments about your criminal risk factors, but these demonstrate your substance abuse, your lack of consistent employment and your risk of re-offending. They are not written from a disability lens which indicates that your brain injury has led to capacity issues in social interaction, poor problem-solving, impulsivity, your poverty, your ability to manage your emotions and your poor employment history.

**Removal of the Access Lists**

I haven’t read or heard much from the lived experience community about the access lists. My understanding is that List A are conditions which are currently likely to meet the disability requirements of the Act and include, amongst other conditions, intellectual disability and autism. My understanding of what is proposed is that a person with intellectual disability with cognitive functioning below 55 will – under the proposal - have to undergo a re-assessment of their cognitive functioning – even though this is not going to improve over time – and also their functional capacity - to prove that they in fact are eligible for the scheme. This is actually bordering on abuse in my opinion as these assessments are difficult for the participant, and can be soul-destroying if you realise you are not doing “well” in the assessment. People with the disabilities under List A are likely to be the most vulnerable members of our community. In addition, if an initial assessment determining your intellectual disability was recent, this actually would render the re-assessment invalid if it was repeated within a short time frame of the original assessment, due to practice effects.

**Therefore, in order to provide sufficient support to potential participants of NDIS to achieve true Choice and Control and receive NDIS packages that meet their disability needs, whilst also providing equality and consistency in decision making, I submit the following summary of what is required:**

* Funding of **assessments** to document evidence of disability, in addition to funding assessments of functional capacity of people with psychosocial disabilities, when required. Funding to include enough time to properly communicate and develop a trusting relationship with the potential participant and those closest to him/her.
* Funding of an **allied health professional** of a person’s own choosing, who is, first and foremost, caring, and secondly, has a very good understanding of psychosocial disabilities, in order to properly articulate the potential participant’s functional incapacity, in addition to documenting their interests and skills and strengths.
* Funding of **case managers** within NDIS Plans for participants who are vulnerable and cannot advocate for themselves, such as particularly vulnerable groups, such as those without families, in prison, hospital, homeless, particularly those with more than one disability, such as a psychosocial disability and cognitive impairment. This is imperative in order to ensure ALL needs are met and services are coordinated, including services provided by state-based services such as health or justice. This includes those who do not understand their Plans, have drug and alcohol issues, unmet physical health needs, do not communicate adequately, may not even answer phone calls or open mail, and do not know how, where and who to hire as support workers and allied health professionals.
* Funding of **support coordinators** who have specialist psychosocial disability skills and experience.
* Provide **easy read versions** of ALL documents in many different languages.

The cost of providing these extra supports is far, far less than the emotional and financial costs of continuing to allow people with psychosocial disability to languish in despair, neglect, poverty, loneliness, hopelessness, poor physical health, and with low expectations and with a 25-year reduced life expectancy. It is also less than the cost of re-traumatising them by making them re-tell their stories, such that they end up in hospital because of the trauma that comes with applying for the NDIS or seeking a review.

Sarah Sutton