Submission to NDIS Review 2023

Background

I am currently the CEO of Community Care Options Ltd in Coffs Harbour. I have worked in the disability sector for over 41 years in a range of different settings. My company currently provides both NDIS and aged care services and has done so for over 30 years. I have witnessed many changes in the disability sector over 40 years, not all of them good, but have not experienced this level of disarray and confusion. I have worked for health, community services, ADHC, wherever the poisoned challis of disability has been placed. I trained in a large residential facility as a Disability RN, located to the community (group homes) under the Richmond Report and was involved in deinstitutionalisation for many clients in Western Sydney. I am qualified as a Behaviour Specialist, working with very complex disabilities. I was involved in the Boarding House Reform Project, Therapy Services Projects, Managed a Community Access Team of case managers, psychologists, therapists, worked in work skills training areas, day programs and respite services. I was a Senior Manager for ADHC responsible for its accommodation and respite services on the North Coast of NSW. I was also one of 12 Senior Practitioners in NSW focussed on quality service improvement and best practice in disability services. I have spent my life working in this great sector, and am a very passionate advocate for the rights of people with disabilities. I am also an advocate for social change, common sense and a system that is sustainable and that Australia can be proud of.

Whilst the intent of the NDIS has been honourable, the implementation and current execution have way layed this intent. There seems to have been a firm opinion established by NDIS personnel from the get go that traditional disability services have been ineffective and not necessarily operating within a client's best interests. There have been many articles talking about captured client's - where clients get all their services from one provider and have had little choice, and that this has been seen as a conflict of interest. Traditional disability providers were required to operate within the state based funding system, and clearly that system had limitations. However, these services ran on the smell of an oily rag often, provided excellent and caring services by and large, and worked collaboratively to find local solutions for People with a Disability (PWD). Impressions from early interactions with NDIS personnel was that traditional providers could not advocate for clients, and had no place in assessment and planning meetings. Somehow our experience was seen as a conflict of interest. Maybe there was concern that we would advocate for much more than client's needed? Certainly I have seen many clients who I would advocate do not need as much funding as they are currently allocated.

Over funding has to a high degree disabled many PWD. It has also benefited many who were kept outside of eligibility under the previous state based system due to lack of funding.

<u>Example</u>

My service, Community Care Options (CCO,) were individually funded for many clients prior to the rollout of the NDIS, under programs such as Attendant Care, Respite packages, Individual Support Packages. One such client JL was allocated funding of just over $110,000 per annum.

CCO supported this client to move out of home to independent living. He had many hopes and dreams – buying a car, having a lawn mower repair business, finding a girlfriend. He was highly motivated and fiercely independent. He bought a car, found permanent accommodation, started his business.

Following assessment by the NDIS he was allocated in excess of $300,000. Even though CCO was returning unspent funds for this client previously each year. Client's see a large amount of funding and want to use it just because. This client requested sleepover support every night, so he could use the funding. We did not have capacity to provide this level of support to someone who didn't require it.

JL is no longer our client, no longer has a car, and is rarely seen in the community. I have visited him a couple of times and he has visited me a couple of times when he has needed support with things from someone he trusts. He is solely supported by Sole Traders, yet does not seem to have the independence, motivation and involvement in life he had previously. I would think this is the case for many PWD. NDIS encourages people to use all their funding and more, whether they require it or not. The fear is if you don't use it your plan will get cut. In many cases excessive funding has reduced PWD's independence and interaction with community and opportunities, but rather funds a highly resourced baby sitting service for many.

<u>Example</u>
Another client we used to support for many years with MS – TW, also individually funded prior to NDIS. Lives alone was mobile and very independent, with support a couple of times per week for shopping and cleaning.

Client was encouraged to utilise sole traders by sole traders. Client contacted us as his COS, regarding his concerns with a Sole Trader that he had engaged. Advised us that she was manipulating him and he was feeling taken advantage of. Sole Trader driving him to Port Macquarie to pick up her jet skies, whilst charging his NDIS package for both her time and the km's. Dropping him at appointments and then going to do her own shopping during his service time. Taking her children to services with client. Invited client to a BBQ at her home. Where he was stranded and had to stay overnight because he had no way to get home. Sole Trader invited friends, taking drugs, drinking and taking photos whilst client was present. Our service advised him to dismiss the Sole Trader as she was clearly taking advantage of him. He only reported these events 1 year later.

A week or two later he came to our office and showed us text messages from this Sole Trader saying she was sorry and would he take her back on his support team. She needed the money, would improve etc etc. The client was feeling bad and was considering re-engaging her. This is clear and brutal manipulation by staff working in the sector that do not have to meet any standards, expectations, or accountability.

I attempted to report this to the NDIS Commission via their Portal. I was unable to submit the form without filling in every box which I was unable to do because I did not have all of the

information as they were not my employee. I then emailed the NDIS Commission advising that I wanted to make a reportable incident, but was unable to do so. Emailed the details that I had. No one has contacted me about this issue. Can provide name and address. People will not report if it is difficult for them to do so. It should not be this hard to bring issues of concern that need to be investigated to government's attention.

The client was then contacted somehow by a defacto couple, who sought our permission as the COS and Plan Management service for the client to go to their property and engage in riding their ride on lawnmower and cleaning their pool as suitable activities for the client to engage in. We felt that this was exploitive and declined. The client was encouraged to move their COS to someone else, which is fine. We do however still pay invoices for this client and it seems he now gets 8-11hrs support per day, and requires sleepovers? I still have concerns that this client is being manipulated and exploited. I would see it as a conflict of interest to have staff supports that are related? Client's like TW are very lonely and think the best of everyone, this leaves them open to exploitation.

I believe there are many participants that achieve great outcomes from the NDIS and there are many who do not. High amounts of funding does not guarantee any level of care or services. I believe that the NDIS does not know how to measure outcomes achieved from funding. Goals are inadequate at best, measuring real outcomes can be difficult if this is what we measure them against.

<u>Example</u>

Client in Coffs Harbour SW – appears to be receiving 24hr care. Support staff (Sole Traders) sit in their cars for the duration of the service. Many have never me the client that they are charging the NDIS to support.

No care let alone value of care is being provided to this client. Would tax payers think this reasonable and necessary??? Have raised concerns about this client with the NDIS Quality and Safeguards Commission, who referred me to the police, and said this was not their responsibility. Phoned the Police to request that a welfare check be done on this client, as I believe they are locked in their house from about 6am each morning until 5-6pm daily, with NO interaction from staff. The local police advised that the matters I raised should be taken up with the NDIS Commission. To my knowledge Police did not provide a welfare check or sight this client. Client's sister I believe is self managing her brother's funding, and paying Sole Traders to sit in their cars??? This amounts to no level of care to this client for probably a colossal amount of funding. It is very understandable how people who try to report issues give up and there seems no suitable avenue or care from the NDIS Commission. If I had received this report I would have ensured a full investigation of these circumstances. I only have it as hearsay but have also sat outside the client home and watched staff sitting in their cars. Both myself and the local Disability Advocate have attempted to raise concerns re this client with local NDIS office. Again recently I requested police do a welfare check. They attended spoke to a Sole Trader and left without citing the client, who was screaming inside the home. I fear this will end up being another Ann Marie Smith event. Neighbours have raised concerns over time re the care of this person.

I could continue to give examples of client's I am aware of who are being exploited, both financially and neglectfully it terms of the appropriate care and support and skills of staff that they require.

We have circumstances where identified informal supports ie friends in a client's plan have suddenly become Sole Traders and are now paid supports. Is that the intent of the NDIS??

We should be encouraging development of social networks and informal relationships as this is true independence and integration. The NDIS is making client's dependent upon their support staff, with no real focus on skill development or empowerment. These staff become very dependent upon this client as their meal ticket. The Sole Trader cannot afford to lose their income. We have observed messages on local facebook pages where a sole trader who is unavailable to work with a client is doing a 'shout out' to other Sole Traders to help them out. People being exposed to what level of vulnerability?

As Registered Providers we must have clear processes in place for conflicts of interest. Policies, procedures, forms, waivers etc etc. Separation of roles and functions eg cannot be a Support Worker and a COS and a Plan Manager, yet I am aware of circumstances where a Sole Trader is listed as a client's Next of Kin, is her COS, and also her Support Worker – raking in in excess of $250,000 from what I can see. I am a CEO, I don't make that much for ensuring that our service meets quality expectations for our 2,000 clients per year. One of our ex staff is working with a client and now their husband also works with the client. People suggesting their friends to a client as a new worker option. No experience required. No understanding of the NDIS, no policies, no procedures, no complaints process, no conflict of Interest???? I am sure this is not unique to Coffs Harbour but is very widespread.

Terminology

The NDIS has had negative press since its inception. Many were dubious about the terms Insurance and Scheme. Insurance should be about giving client's assurance that their needs will be met. People do not have a lot of confidence in Insurance agencies. It has definitely proven to be a scheme/scam for many. The word scheme does always have positive connotations. Trust is critical to PWD, they don't trust the current system, and it has not been an easy system to navigate or understand. The word participant, has a very passive feel to it. They are participating in their own lives and the scheme but not in control of it.

<u>Recommendation</u>

For client's (PWD) and other Australians to have confidence in the scheme, maybe a rebranding and new terminology might be helpful. The government should want this review to reassure people that real and sustainable changes are occurring. What about **Australian Disability Services (ADS).** Rather than protecting the most vulnerable, the NDIS has become the lifeboat for everyone in the community. A clear definition of disability would be useful. State government services previously had very clear definitions of what was and was not considered a disability and effectively managed its services within funding allocations. It should consider the functional areas of need that people have, not their goals and wants. I have seen a number of client's allocated NDIS funding who do not have a disability. eg They have a medical condition such as COPD. The NDIS cannot be all things to all people. There are many conditions

that are disabling – eg diabetes, cancer, dementia, etc etc. This does not make them a disability per say. What are Health's responsibilities in supporting client's with these needs?

PWD should be entitled to access the same services and supports as anyone else in the community. This includes health and education services. Since the implementation of the NDIS we have seen the buck pass significantly. Health services, therapy etc now cost PWD more than ever before, and if the client has NDIS funding health will often not prioritise them for care and services.

Example

Currently we have an NDIS client AT who has MS. She requires dialysis several times per week. In attending dialysis she was dropped during transfers and required hospitalisation for several weeks due to a breakage in her hip requiring surgery. She was discharged home last week. She has a skin condition that is very concerning and a pressure area that requires ongoing wound care. GP made referral to Community Nursing for wound care. They referred it back to us. Client is not funded per say for specialist nursing care and we do not have the resources to provide this level of support. They may provide it if she agrees for them to bill her NDIS package. This seems somewhat discriminatory to me. The client is having to pay for the poor care that she was provided (requiring hospital admission and surgery) by Health in the first place.

Recommendation

Government at federal and state levels agree on what is included in the NDIS and what is not. PWD should not be discriminated against in terms of access to appropriate health and medical support, and should in fact be prioritised for this support, as vulnerable Australians.

Reform 1 – RISK MANAGEMENT

For me this is the most critical flaw of the NDIS. Inadequate risk management, inconsistent application of standards and expectations.

Reform 2 – Financial Management – Poor implementation of an incredibly complex system has led to over spending and budget blowouts. Put all the money into the sector. Most plan management fees are going to the finance sector – accountants, financial planning services etc. This has not helped to build a resilient disability sector, but seen the erosion of robust systems and processes, and sector goodwill. We are no longer an integrated and collegic industry (sharing best practice) but a competitive one. All fighting for the dollar, the client, the staff.

Reform will not be possible until the NDIA is prepared to make some hard and fast rules. We cannot forget this is a welfare system, protecting some of Australians most vulnerable. Australians want to see people with a disability protected and living good lives, but the cost and the benefit must be sustainable.

Recommendation

Budgeting – align all participant plans with the financial year. This would make it easier to track funds commitments and participants and providers will always know when their plan is due to expire, and how long their funds need to last.

Previous state government systems and processes worked reasonable effectively, they just didn't have enough money in them.

Gatekeeping of the sector needs to be undertaken by people that know what they are doing. Most NDIS Assessors/planners have little to no experience in the disability sector. Guidelines need to be such that they are fair, equitable and routinely applied.

Assess once – for a reasonable plan. Allocate funding to a Registered Provider (not finance sector) & have a well coordinated range of programs and services for PWD to access.

Reassess if client needs change. This will eliminate continuous inappropriate reassessment, cutting of plans, legal costs, and ensure that client's confidence in the system and what they are allocated is reasonable and protected. Not forced to spend funding just to ensure it won't be cut in next plan.

CPI increase each financial year.

Funds allocated to a Registered Provider to manage and acquit. Client can choose provider and also choose a range of other supports. Less risk of fraud. Should not require Fraud Taskforce. Registered Provider to ensure that spending matches client's needs and is reasonable and necessary. Currently there is much confusion about what COS and Plan Managers do. One pays bills and invoices, the other connects client's to services. Some client's have both, or one of them. Paying bills not sufficient oversight of appropriate spending for needs.

The system is too complex. After 10 years many participants, carers, service providers still do not understand all of the components and what they are supposed to be getting. Current plans are not worth the paper they are written on. They have no substance.

Price Guide – throw it away. Providers and awards mean that we have to pay staff the same rate regardless of what service they provide eg domestic assistance and community access – one rate of pay but two different prices in price guide. We pay staff more for doing less.
I'm not sure who comes up with the prices? Could they be simplified and rounded eg instead of $67.12 per hour - $65.00 per hour.

By setting the price NDIA has encouraged everyone to bill for this price, including sole traders. I assume the price was set to cover provider overheads, but now has become a point of overpayment to sole traders who often do not have the skills, training or oversight required. Participants have become a cash cow. Why work for a registered provider at $30 per hour if you can just get an ABN and set up your own business and get paid $67.12 per hour.

Simplify the price guide and have a provider price and a sole trader price. Sole Traders should have to apply and be approved by the NDIS Commission.

Example

My company – not for profit, existing over 35 years supporting people with a disability in our local community, has lost approx., 25 staff who have set themselves up as Sole Traders and then coerced our client's to engage them as sole traders. It matters not that I have employment contracts that prohibit staff from canvassing or approaching client's etc etc. As a Plan Management provider we pay the invoices for many Sole Traders, so we see what they are working and with whom. Many of those staff were people who needed supervision and support, to ensure that they maintained professional boundaries and appropriate care. I have concerns about some of them working as Sole Traders. I am aware of Sole Traders who are working 20 hrs straight with client's, and wonder at the level of focus and care that is being provided to client's. Sole Traders take no care with their invoicing, eg days of support, times of support , and exactly what line item they are supposed to bill against. They have no ideas about how to write an invoice let alone appropriately care for some very vulnerable and high needs client's. As a Not for Profit we must operate under employment awards and industrial standards. These are also not regulated for Sole Traders. I am wondering whether providers like myself should seek some sort of class action against the NDIS for putting us in a situation, where we cannot enforce our employment contracts and protect our business.

Rule 1 - Clients should NOT self manage tax payer funding.

Rule 2 – One assessment for a plan of supports for a permanent and lifelong disability, based on functional areas of need, NOT goals and wishes.

Rule 3 – All providers of disability care must be NDIS Registered. NOT financial planners, and funds holders. The same standards of care need to be provided across the sector.

Reform 3 – Build sector and resilience – we are currently creating dependence.

Currently system is too complicated and disjointed. Inadequate risk management for complex people.
PWD require well coordinated, accountable, wrap around services. We need cooperation, not competition to build a great sector. We are losing our skills base and regulated service delivery through the advent of Sole Traders in the sector. Unskilled, unregulated, different rules, lack of clarity, causing providers to lose staff and client's.

Once again we have a one size fits all approach with no thought to what else can support the NDIS eg education, health services. Let's put therapy services back where they belong, in early intervention and schools – continuous access until aged 16.

Experienced professionals that know what they are doing.
Not sure what the NDIS Commission does? Certainly not regulate.
All providers should be subject to the same audit and quality scrutiny, and all should be registered, particularly if providing Coordination of Supports.

Current NDIS plans are poorly written and poorly interpreted.

Here is an example of a participant NDIS goals as written by an NDIS Planner –

I would like to regain a sense of place and purpose in the world.
I would like to be supported to engage in social activities.

Lots of money is being wasted on social support, not skill development. Poorly written plans that don't even advise of what the client's disability needs are, are not conducive to effective care and support. The above client does not wish to engage in social activities and is now paying her informal supports for the privilege of their friendship. First goal is really open to interpretation. Funded for $83,500 per year. Mostly has medical conditions not defined disabilities. The sector has become a highly costly baby sitting service.

We are not building the sector the NDIS has dissected it. We need to be realistic that not all needs can be met through the NDIS, this is blowing out costs.

There should be some identified block funded supports and services that provide a safety net for PWD. Siloed services create gaps that people fall through. Effective risk management is needed so this does not happen. We spend millions of dollars on royal commissions and then create the very systems that fuel abuse, neglect and exploitation.

Sole Traders are recommending their friends, family members ect to client's which creates a huge conflict of interest. Client's feel obliged to accept them.

Reform 4 – Accessability, Continuity and Accountability
It's NOT the secret service!!! That's how it operates. It is designed to keep people at arms length, not help them - either PWD or service providers.

Disability services need to be accessible, local, helpful, provide genuine oversight and government needs to be accountable.
Return to government portfolio, with State and Regional Managers/Directors

Local offices providing information, access, complaints management, **assessment,** crisis support.

Regional Teams of Professionals - OT, Physio, Psychologist, Speech Therapist, disability Representative, Behaviour Support, other?
Who provide structure and support for complaint resolution and behaviour management – restrictive practices regulation. Support for regional providers.

Not all services should be individualised – this increases costs

Services that should be block funded include –

Accommodation Services
Respite Services
Day Programs to some extent.
Therapy Services – either in health or education

Reform 5 – Reasonable and Necessary – as decided by the client. Discretionary use of funds – approved by provider as long as stay within budget. Many people are better off under the funding provided through the NDIS, but many are not because of the prescriptive nature of funding line items.

PWD know what they need and want. It's the same as everyone else. However, it is not a wish list, it is, to give safety, suitable care and continuity of services for those who need them. Being goal based is a farce if we consider the quality of assessments and NDIS planning. Again having multiple budgets is confusing for client's.

Allocate a budget, the client manages it with the assistance of their chosen Registered service provider. Wrap around service, that provides care coordination and financial management oversight.
This is not a conflict of Interest, but necessary for many client's with a disability.

The NDIS talked about 'captured' clients, some are more captured than ever, by Sole Traders.

Have a reasonable and necessary plan that can be tailored depending upon individual needs. See Attached reasonable and necessary plan.

Reform 6 – Permanent and Lifelong – requirement for access
Comprehensive assessment on referral to Australian Disability Services.
Regional panels have the discretion to make recommendations outside of service guidelines.
There is always an exception to every rule.
Assessed for needs, not wants, not goal based.
Assessed for approx. hours of service per week – reasonable and necessary.
Travel allocation based on location and needs not prescriptive (within limits)
Change of Circumstances – client may request a review of circumstances through Regional Panel.

As per Reform 1
Budget allocated to Registered Provider, client may spend as needed in consultation with provider
Equipment purchases over $500 to be approved.
Some discretionary funds for unforeseen emergencies, respite (if carer), and holiday support.

Reform 7 – Everything else that is not included here.
Providers set prices (within limits) based on client care and support needs.
Allocation of funds for care coordination and package management as per current home care packages program.
Build the sector. The road we are on is very slippery!!!
In 42 years in the disability sector this is the worst system ever introduced.
We fought for years for adequate funding to be allocated to this sector. There is. It's just poorly managed.

Recommendations for changes that could be implemented easily and save money

Financial Management

Price Guide

Risk Management

Reasonable and Necessary

Sole Traders

Sorry I have left myself short of time in completing this submission.
It may seem incomplete and disjointed.
I will review and resubmit.

Regards
Deb Ryan
CEO
Community Care Options Ltd
[redacted]