COMMUNITY LIVING ASSOCIATION
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Community Living Association
Growing communities where all people are valued

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NDIS Review Submission – Part 1

The Organisation's Views

Dear NDIS Review Panel,

Community Living Association

Community Living Association Inc. (CLA) began in 1989 as an Independent Living Service for people with intellectual disabilities. Subsequently, we have established services for people with intellectual/cognitive disabilities who are:

- Homeless or at risk of homelessness;
- Young people with a Child Safety and/or Youth Justice experience; and
- Parents, often where their children are subject to child protection interventions.

CLA has auspiced the formation of other services through our developmental practice and approach. This includes:

- A sexual assault and victims of crime service for people with intellectual disabilities (WWILD).
- A housing company, run and owned by people with intellectual disabilities (IYHG).
- A workers' co-operative owned and run by people with intellectual disabilities (NCEC).

CLA's responses – which also include working with people around trauma, mental health, addiction, substance use, criminal justice, Child Safety, physical health and wellbeing, and money management – have developed from the issues raised by the CLA constituency.

We use the term 'constituency' or 'constituents' instead of 'clients' or 'service users' to emphasize that the organization belongs to the people who use its services and exists for them.

Constituents and their significant others have formal power in our organization. They have membership rights, including the right to stand and vote on CLA's Management Committee (Board). One third of our board is reserved for constituents, and another third is reserved for their family members.

CLA's NDIS Services

CLA Inc. is a registered NDIS provider and provides a range of supports including Allied Health, Core supports, Groups, Support Coordination and Plan Management. CLA does not provide SILS, SDAs, Consumables, Capital and Behaviour Supports.

We also work with people who have a psycho-social disability in the NDIS, with many constituents with intellectual/cognitive disabilities having dual-disabilities and diagnoses.

We do not operate within a Disability Support Worker model. Most of CLA Inc. staff are qualified Social Workers, whilst others hold tertiary qualifications in Human Services, Counselling, Psychology and/or Public Health.

Summary of CLA's Submission

Our submission includes the experiences, opinions, and recommendations of:

Part 1
Our NDIS Staff and Team Leaders via direct practice, staff supervision, and organizational management.

Part 2
NDIS participants we support, and their family members and informal supporter(s).

This is supplemented by a reference list of relevant research and literature that serves as an evidence base in support of some of our statements and opinions, as well as providing additional context and information for further reading if needed or desired.

Thank you for the opportunity to contribute to the future of the NDIS.

Yours sincerely,

CEO / Coordinator
CLA Inc.

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Part 1 – The Organisation's Views

Recommendations

1. Advocacy

Advocacy supports are a crucial safeguard for participants, particularly those with an intellectual and/or cognitive disability.

Everybody on the NDIS should have access to disability advocacy services, and access to advocacy services should be incorporated within the NDIS Act, NDIA, and NDIS Commission.

- There needs to be more funding for disability advocacy organisations and legal centres where advocacy support is accessible and affordable for those who do not have the means to pay for a private lawyer.

- If a participant engages in the AAT review process, free counselling and support services need to be made available for them and their supporters. The stress, fear, trauma, and intimidation they experience in this process is excruciating.

The NDIS should recognize that providers and workers can be some of the strongest advocates for participants, particularly when they have limited or no informal supports.

- Recognise the value of certain formal relationships in participant's lives, and if the participant consents or requests it, listen to their perspectives. This is particularly important when a person's disability is not readily visible or observable.

- The NDIS should acknowledge and respond to the difficulties and challenges people with intellectual disability and complex trauma history face in communicating with NDIS.

2. Supports

The NDIS fails to adequately address the breadth of support needs and complexity within the NDIS population.

- The Pricing Arrangements should be overhauled so they no longer restrict participants to Disability Support Workers and/or Allied Health Therapists.

- These are the extreme ends of a spectrum, and an entire middle layer of supports and skilled workers is excluded, particularly those who are tertiary qualified.

Recognize and understand that there are links between various conditions.

- There is an intersection between health and a person's intellectual and/or cognitive disability that can compound impairment(s). If a participant's mental or physical health is poor, general functioning is reduced, and more support is required.

- Provide appropriate funding to enable people with intellectual and/cognitive disability to access ongoing psychological support from experienced practitioners of their choice.

Recognise and support various forms of employment, including micro-enterprises and volunteering.

- NDIS Planners and Internal Review Staff should be trained to understand a micro-enterprise is part of employment and requires employment support. NDIS needs to fund the discovery phase of a micro-enterprise as recommended by the ILC micro-enterprise project. NDIS Planners and Internal Review Staff need to consider and act on Allied Health recommendations in relation to micro-enterprises.

3. Workforce

If the NDIS continues to regulate prices, it must account for differences in the quality of services.

- Providers that have higher classified and permanent staff, provide more supervision and training, and don't believe 90% utilization rates are sustainable for their workers or the supports they provide, should be allowed to offer services under the NDIS.

- There are unmet, complex needs within the NDIS population that these providers can meet.

- Currently, the NDIS structurally prohibits this level of skilled and quality support through the Disability Support Worker model and subsequent Pricing Arrangements.

4. Complex Support Needs

Complex or high-intensity supports are not just medical supports, SILS, or restrictive practices.

- Change the Typical Support Packages (TSP's), Planning Processes, Registration Requirements and Support Items to reflect complex support needs more accurately, particularly trauma and marginalization, and the knowledge, skill and supervision required to work alongside these participants.

Provide block funding to services that work with people with complex support needs, so they can meet that cohorts' support needs.

- Such as offering flexibility and responsiveness, pro-active outreach, holding-in through periods of disengagement, building and maintaining a trusting and safe relationship over time, and have an adequately skilled and resourced staff group (eg: qualified social workers) to do the work.

NDIS should consider implementing creative and flexible family driven solutions to support the needs of complex families.

This could include:

- Block funding for some of the family's support needs to be used flexibly across the family.
- Joint Planning meeting to better coordinate funding across the family
- Finding mechanisms to support organisations to retain staff needed for school holiday support.
- Complex Families require Specialist Support Coordination.
- If one member of the family is managed through the NDIS Complex Support Needs team, then the whole family should be coordinated through that team.

5. Mainstream Systems and Specialist Supports

Support is required under the NDIS to assist people with complex support needs to navigate and engage with mainstream systems. This includes Child Safety, Education, Health, Housing, and the Justice system.

- There should be additional/dedicated funding for inter-organisational collaboration and communication.

- NDIS and mainstream systems need to develop spaces for joint action, for coordinated action and for recurrent interaction. They also need to provide flexibility and openness to address the real needs of those experiencing conditions that exist across systems eg: mental health conditions and intellectual disability.

Specialist disability supports related to mainstream systems should be funded by NDIS.

- NDIS funding should remain the same when people are incarcerated, to ensure people have access to therapeutic supports and skilled workers relevant to their NDIS goals as defined in their plan.

- Currently the NDIS *may* fund capacity building supports that will help people when they're released from prison / detention, however their needs to be more funding for skilled workers (eg. social workers) who have already built relationship and trust with the person. This will ensure continuity of supports, enabling people who are incarcerated to have access to disability specific therapeutic supports to break the cycle of recidivism.

Review the implementation of the principles set up by COAG to determine the responsibilities of the NDIS and other service systems.

- Develop tangible mechanisms that effectively and transparently action those principles. For example, ensure specialized officers or targeted projects within the different systems where direct communication between systems and joint action is possible to address the needs of people with disability promptly and effectively.

6. Parents who have Intellectual and/or Cognitive Disabilities

The NDIS should recognize and fund the need for tailored parenting support for parents with intellectual disabilities and adequately fund such services.

The NDIS should fund comprehensive assessments that capture the complex support needs of individuals with intellectual disabilities who require specific parenting support.

- The Child Protection system and NDIS should work together to streamline the process of accessing necessary support services for parents with intellectual disabilities.
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- Stakeholders should prioritize joined-up approaches across systems to mitigate system failures and ensure that parents with intellectual disabilities receive adequate support.

7. Plans

Make NDIS plans more flexible and increase choice and control.

- **Allow people to spend their funding as they like, without the restrictions of support categories.**

Some supports can remain stated, such as Behaviour Support, Capital, SILS and SDA, but the vast majority should be accessible to anybody with a NDIS plan.

- **Access to Support Coordination should be universal.**

Planners and LACs need to be better resourced and skilled to meaningfully assist participants' access to supports and implement their plans – more than just directing them to where they can find information or request support, needs a 'walking alongside' approach.

8. Plan Assessments

If the NDIS is going to maintain the existing planning process, specialized branches/planners for each type (or differentiation) of disability, and complexity are needed.

- Only planners who have knowledge and understanding of intellectual disability should be developing plans for that cohort, similarly with other types of disability.

- Specialised planners are needed who understand and can recognize complexity, marginalisation, trauma, and the subsequent needs of this population.

Whenever possible, participants and their supporters should be given the choice of having the same delegate for their subsequent planning meetings.

- If this is not possible, thorough meeting notes should be put on file so the participant does not need to retell their trauma history.

- This will save time going through administrative tasks and focusing on goal setting, barriers, and strategies for next plan.

NDIS Planners and Internal Review Staff need to consider and act on Allied Health recommendations.

- They need to clearly justify when and why they do not follow the recommendations of Allied Health Reports.

A delegate from the Home and Living Team needs to be present at plan reassessment meetings.

- They need to make a decision not just based on reading reports and supporting documents remotely, but to actively engage in the planning process with the participant and their supporters.

- There needs to be a clear framework and guidelines on how the Home and Living Team operates.

- A contact phone number and email for the Home and Living Team needs to be included in the participant's plan.

9. Internal and External Reviews of Decisions

The NDIS should have clear, fair, transparent, and timely processes in response to plan review requests, and follow those processes.

- Inform participants of all necessary information at the earliest opportunity.

- Increase communication around NDIS plan reviews and roll-overs of plans – what is going to happen and when, what information can and should be shared by the NDIS and Planner.

- The NDIS should provide participants with clear reasons for the decisions made about their plan, including clear reasons why funding is cut. Seeking clarification of a rejection or reduction in funding should not require a PIA or FOI application.

- Uphold the principles of natural justice and procedural fairness.

It should be possible for new information or reports to be considered and responded to by NDIS without having to require a full plan re-assessment process.

- The new plan variation process goes someway to addressing this, but it remains unclear and poorly understood by many within NDIS, providers, and participants.

The AAT process should not be the only avenue for external and/or independent reviews for NDIS decisions.

- As has been recently acknowledged by the Federal Labor Government, the AAT is a fundamentally unfair process for NDIS participants and their families.

10. Provider Registration

Review the role of registered providers in the scheme, and the requirements of registration.

Currently there is little incentive to become a registered provider, particularly given:

- The diminishing number of supports that require registration,
- The ability for most participants to access plan management,
- The high administrative and cost burden of registration, and
- The minimal gain(s) registration seems to entail.

Require some level of regulation for unregistered providers, to ensure quality supports are delivered and participants are safeguarded against problematic practices and supports.

A Profile of CLA's NDIS Participant Population and Supports

Intellectual and/or Cognitive Disability

CLA predominantly supports people with an intellectual and/or cognitive disability within the NDIS. We also support people with a psycho-social disability.

Almost anything negative that can happen in society does happen disproportionately to people with intellectual and/or cognitive disabilities, and their capacity to respond to negative experiences is impacted by their disabilities.

Thus, within the population of people we support, there are many co-occurring issues and support needs, including:

- Trauma histories
- Attachment Disorders
- Personality Disorders
- Exploitation and Violence from Peers
- Domestic and Family Violence
- Mental Health, including suicidal ideation and self-harming behaviours.
- Physical Health, including complex health management plans.
- Recurrent Crises
- Being formally excluded ("banned") from mainstream and other disability specific services
- Addiction
- Substance Use
- Housing instability and homelessness
- Involvement with the Justice and Youth Justice systems
- Involvement with Child Safety as children, and parents, and
- Family Units with more than one person with a disability.

Model of Support

CLA's model of support is based on the core needs of the people we support, particularly complex support needs:

- A focus on building capacity in decision making, relationships, resources, and knowledge wherever possible,
- Developmental practice that aims to build communities and social inclusion,
- Proactive outreach to overcome exclusion,
- Longer-term relationship building to achieve connection and understanding,
- Deep listening to understand core messages,
- Flexible services to hold in during chaos and disruption,
- Open-ended support to feel safe and achieve, and
- Creative support to open up opportunity.

This includes workers who are trained and skilled in trauma responses for people with an intellectual and/or cognitive disability:

- Understanding the purpose of the behaviour ie: what is the person trying to communicate.
- Observing and identifying triggers.
- Identifying unhelpful (or maladaptive) coping strategies and their purpose.
- Managing risk and safety – for the person, the worker, and others.
- De-escalation strategies.
- Emotional regulation and co-regulation.
- Psychoeducation.
- Practicing unconditional positive regard.
- Distress tolerance skills.
- Use of simple, and person-centred, language.
- Not relying only on verbal communication ie: using drawings, movement etc.
- Maintaining consistent and purposeful boundaries.
- Grief and loss counselling.
- Support to develop adaptive behaviours.
- Support to gain insight and introspection.
- Support to understand and process risk and protective factors.
- Support to develop an understanding of safe and healthy relationships.
- Support to make informed decisions, to provide informed consent, and to exercise dignity of risk.

In our experience, the kind of complexity we witness in providing NDIS supports, the high level of needs, and the skilled and supervised workforce needed to support these participants, is missing from the NDIS.

The current structure of the scheme isn't designed for this population, yet they are some of the most vulnerable and marginalized.

The below sections flesh this out in more detail.

Problematic Assumptions and Conceptions within NDIS

NDIS Assumptions	Problems and Concerns
Disability	
The different needs within the disability population are not adequately considered.	This creates fundamental inequities: differing impairment types, complexities, and access to social capital is invisible/not recognised. NDIS was not designed for people with intellectual and/or cognitive disabilities, particularly those with borderline, mild, and moderate intellectual disabilities.
Participants identify with disability and can articulate its impact on their lives	People with intellectual and/or cognitive disabilities often do not identify as having a disability due to stigma, discrimination, and self-identity/concept. Masking and minimising the effects of their impairments is common.
All NDIS participants want to engage with NDIS.	Many people find engaging with NDIS difficult (due to communication difficulties, trauma and not identifying with ‘disability’). Significant support is required to enable active participation and engagement in decision making processes.
Disabilities can be easily observed and assessed through minimal engagement and/or assessments with allied health (OT), NDIS professionals (e.g., planners) and NDIS intermediaries (Support Coordinators and Plan Managers).	The impact of intellectual and cognitive disabilities is largely hidden and requires knowledge of both these types of disability. The person also needs to be known and understood, which requires building a trusting relationship over time. Challenges faced by an individual are frequently masked and are not reflected in formal allied health reports or by NDIS professionals and planners.
Complexity	
Complexity is understood as medical complexity in Pricing Arrangements and Registration Groups (as defined as high intensity supports and 104 registration requirements).	Complexity is not just the presence of medical conditions. NDIS does not adequately recognise the intersection between trauma, and intellectual and cognitive disabilities. Trauma has a significant compounding effect on impairment(s) which are not currently addressed or responded to within NDIS.

NDIS Assumptions	Problems and Concerns
The "Social, Community, Home Care and Disability Services Industry Award 2010" (SCHADS) 2.4 or 3.1, reflect an adequate level of knowledge, skill, training, and experience to engage in complex work.	Working with intellectual and cognitive disability and the intersection of trauma and other disadvantage, requires knowledge, skills, training, supervision, and support that is not reflected in the lower-level SCHADS classifications NDIS enforces.
The recognition of Complex Support needs within the NDIS Operational Guidelines informs the Pricing Arrangements sufficiently. The Complex Support Needs Pathway is adequate for responding to complex needs.	Working with complexity requires both Case Management (Support Coordination) and ongoing, regular front-line skilled casework to be effective and implemented. Currently only case management is funded. Though recognized in the operational guidelines, complexity is not reflected in Pricing Arrangements and available supports. Furthermore, there is not adequate funding for the types of supports this cohort needs (beyond Specialist Support Coordination).
Psycho-social disability requires a higher skill level (Level 4.4) than other types of complexity within disability (Level 2.4 or 3.1).	Similar recognition of the need for higher skilled supports should be applied to people with cognitive disability and complex support needs.
Supports – Disability Support Work	
The vast majority of support needs and goals can be achieved with Disability Support Workers, whose skills and responsibilities reflect a SCHADS Level 2 classification.	There is an over-reliance on 'Core' Disability Support Worker supports within NDIS. This restricts choice, can increase risks, and fails to adequately address the breadth of support needs and complexity within the NDIS population.
Supports – Capacity Building	
Allied Health (including Positive Behaviour support plans) can provide time-limited intervention (assessment and intervention report/training) to effectively direct Disability Support Workers roles.	To effectively assess support needs and develop appropriate supports for many people with an intellectual and/or cognitive disability requires building a safe, trusting, and consistent relationship over time, with workers who are skilled at observing, assessing, and intervening every day, in a person-centred way, to dynamic and changing situations.

NDIS Assumptions	Problems and Concerns
	To implement PBSP's and Allied Health interventions for people with complex support needs, often requires skilled workers beyond the current classifications recognised by NDIS.
Time limited Capacity Building (eg: 10 sessions a year) with an Allied Health Professional, should automatically increase someone's capacity.	Allied Health assessments often focus on functional behaviour (e.g., daily living tasks) without considering or capturing the complex social conditions people are facing. Capacity building work where people face significant complexity is often slow, consistent, and complex work. Change can often only be seen after many years of active engagement. This is not adequately reflected or funded in NDIS.
Supports – Support Coordination	
Case Management (Support Coordination) must be separated from direct, front-line supports.	For some people with an intellectual and/or cognitive disability and complex support needs, multiple relationships aren't desirable. Relationships can be unsafe, taxing, hard to build and hard to manage. An alternative model of support for these participants is one that is holistic, rather than segmented and compartmentalised. Many Support Coordinators (SCs) have a limited relationship with the person they are providing that support to, partly due to the NDIS Model which restricts support coordination hours and focuses the role on non-face-to-face administrative tasks. - A lack of relationship can hinder choice and control for people with an intellectual and/or cognitive disability, not increase it. - Despite limited relationships, SCs can exercise power over participants' NDIS Plans, as their roles include connecting and coordinating supports, and managing budgets.
A disconnect between the skills required to do case management (Support Coordination) and front-line work (Direct Supports), reflected in NDIS price limits for these supports.	Working with complexity and skill does not just occur at a Case Management (Support Coordination) level.
Workforce	

NDIS Assumptions	Problems and Concerns
The assumptions in the Disability Support Worker Model are problematic. - The expectation that over 90% of workers' time is billable NDIS supports, also referred to as 'utilisation rates'. - Supervisors who are a few pay points – not levels - above the staff they are supervising. - Disability Support Work is done by workers on base-level SCHADS classifications ie: Level 2. - Complex support work is done by workers on SCHADS Level 3.1-3.2.	The Disability Support Worker Model and subsequent Pricing Arrangements incentivises low-skilled and low-quality support work. - It monetarily rewards providers who hire lower classified workers, provide less supervision and support, and casualise their workforce. - It monetarily punishes, and makes it financially unviable, to be a provider that offers higher quality support with tertiary qualified staff, who have job security and tenure, regular supervision and training, and access to debriefing and reflective practice. The starting point in the SCHADS award for tertiary qualified workers is Level 3.3 and 3.4. - If a worker is tertiary qualified and has experience, they should be on at least Level 4. - In relation to other social and community service sectors, as well as in similar government jobs, individuals with SCHADS related tertiary qualifications generally start at Level 4. Thus, the NDIS excludes an entire layer of skilled workers, who are trained in providing these supports and have professional ethics and obligations, from the disability sector and subsequently from NDIS participants.
Providers	
Providers are profit-driven, growth oriented, want to 'capture' the market, and act in their own self-interest for monetary gain. When providers advocate, or support people to self-advocate for their needs to NDIS, the assumption is that this is innately self-serving.	'Conflict of Interest' policies that are founded on these assumptions, and the recent moves towards restricting Support Coordination to providers that offer that person no other supports. A blanket approach to addressing conflict of interest within NDIS providers fails to consider the many smaller community organisations, often led by people with disability and their families, who seek to provide holistic wrap-around services to participants. Workers and 'providers' who have developed safe and trusting relationships with people with complex support needs can be crucial in supporting those NDIS participants to advocate for their needs. Failing to recognise the importance of these relationships for certain NDIS Participants can restrict their choice and control, lower their safety and increase risk.

Structural problems within NDIS

Structure	Problems and Concerns
Individualized Funding	- Has removed the ability to do community development work, including developmental practice that focuses on building relationships and communities of people with an intellectual and/or cognitive disability for greater social inclusion. - Has not allowed for flexibility, responsiveness, pro-active outreach, and crisis responses for people with an intellectual and/or cognitive disability that have complex support needs. - Currently, the supports available do not adequately reflect, nor meet, the breadth of needs across the NDIS population.
Planning Processes	- Executed by people with no, to limited, knowledge of disability AND differentiation within disability. - There is a preference for using quantitative measurement tools and focusing on personal deficits to secure needed funding. - In our experience, planning processes fail to capture complexity and meet the needs of these NDIS participants, particularly in relation to trauma. - Assumes that all NDIS Participants want to, or can, engage in the planning process, or have resourced supporters to do this. - Assumes that all NDIS Participants can access required allied health reports to access the scheme and for the purposes of plan reviews. - The only option for those with complex support needs, impaired decision making and no informal support is to have Public Guardians appointed. So often, they do not have the time, skills and knowledge required to build a safe and effective working relationship with participants, their Support Coordinator and service providers. Consequently, they fail to represent participants voices during the planning process, implement the approved plan and advocate for participants' human rights and support needs when the plan does not meet their needs. - Concerns with the role of LAC's in the planning process, particularly procedural fairness for participants who have planning meetings with LAC's but whose plan is ultimately approved by a Senior Planner who didn't participate in the meeting. We have observed many instances of disconnection and contradiction between what the LAC may communicate in a planning meeting, and what the person's approved NDIS plan contains.

Structure	Problems and Concerns
	- The introduction of the Home and Living Team is concerning. This has lacked transparency for participants and providers. The process of certain plans being sent to this team for approval raises questions of procedural fairness.
Planning Reassessments and Reviews	- Allied Health reports are frequently ignored. - Requiring repeated (yearly) Allied Health reports when the person's disability, impairments and/or situation have not changed. - Situations where new plans have been created without consultation (against the Act). - Situations where NDIS participants with an intellectual and/or cognitive disability have received phone calls whereby the NDIA has had planning conversations and reassessments with them, without their <u>informed</u> consent. - A Participant Information Access (PIA) Request is required to access planning notes. It is unclear why participants should have to engage in a separate process to access this information, versus it being automatically provided. - When PIA's or FOI's have been submitted, there have been instances where the planning notes and justifications have not explained why funding has been denied or reduced. The notes often quote the NDIS Act without any application to the person's individual circumstances or supports. - The AAT process is not accessible or transparent. There is a marked power differential reflected in access to resources, control and understanding of the information and process, the level of vulnerability and harm (psychological, emotional, financial) experienced by the participant and their family compared to the NDIA, the inability to resolve matters in a timely manner that exacerbates that harm, and the differing impact the decision has on the parties involved.
Communication with the NDIA	- We have found the Call Centre unhelpful at times. Providers and participants will receive different and conflicting information from different call centre staff. - Provider payment enquiries can take months to respond. - Responses can be unhelpful, creating unnecessary work and repetition for providers. For example, not reading previous enquiries related to the same matter. - When payments are not made, limited to no justification is provided. The generic message is 'the supports fall outside of the reasonable and necessary supports in the participant's plan' ie: the plan ran out of funding, so NDIS will not pay for these supports. This occurs even when providers were not told the plan's funding had been exhausted, and a continuation of supports was necessary for the person's safety and wellbeing.

Structure	Problems and Concerns
	- It is not helpful to have Plan Managers make payment enquiries on behalf of providers when a person's funding has been exhausted and the provider has not been paid for supports. The provider cannot communicate directly with the NDIA to explain and justify what the supports were and why they should be paid. Furthermore, the Plan Manager holds no material interest in securing payment for the supports, nor do they face consequences if the provider is not paid.
Pricing Arrangements	- Unnecessarily cumbersome, detailed, and inaccessible. - It has ~820-line items, with each item then having multiple different 'support types'. - This is not disability friendly and restricts NDIS participants exercising choice and control in an informed way. - It is also restrictive in its categorisation, specificity, and pricing. - Adherence to the Pricing Arrangements as they currently exist leads to a high level of administration and bureaucracy for providers and the NDIA.
Intermediaries **(Plan Managers and Support Coordinators)**	- No appropriate mechanisms for accountability in relation to the following: ○ Plan Managers who don't pay providers on time or at all. ○ Support Coordinators who fail to adequately manage budgets. ○ Support Coordinators who make decisions around a participant's support without their consultation or consent. - The absence of accountability assumes that Support Coordinators and Plan Managers always act in participants' best interests. ○ This creates additional pressure on the NDIS participant and their informal supports to monitor intermediaries and providers to ensure they are appropriately supported. - Plan Managers receive contradictory messages from the NDIS. These contradictory statements are: ○ Plan Managers may be liable for a participant's plan spending if not seen to be reasonable and necessary. ○ Plan Managers are not to assess reasonable and necessary supports. - This can lead to Plan Managers engaging in micro-management to minimise their risk and liability surrounding NDIS provider payments. This reduces participants' choice and control over their NDIS Plan and supports.
NDIS Commission and Safeguarding	- Registration is now only needed to provide two supports to our knowledge: Behaviour Supports and Plan Management.

Structure	Problems and Concerns
	- Providers who are registered are subject to higher levels of oversight, administration, bureaucracy, reporting, and costs than those who aren't, without any clear benefit(s). - A whole section of the NDIS market is unregulated ie: unregistered providers. For example, unregistered providers aren't required to have base-level NDIS Worker Screening Checks. - The scope of the Commission is unclear, particularly in relation to Unregistered Providers. - Contradictory and unclear statements from the NDIS around the need for Service Agreements.
Mainstream Systems and Services	- One of the initial intentions of NDIS was to educate mainstream services about the needs of people with disability. This has not been adequately realised. - Generally, mainstream services are not knowledgeable, trained, or skilled in understanding, and working with, people with intellectual/cognitive disabilities. - They subsequently fail to recognise disability and the impacts of said disability on the person. - Eg: Believing that a person who doesn't attend an appointment does so because they lack motivation or aren't interested, rather than they may have a poor sense of time, disorganisation around dates, difficulties planning and remembering, a chaotic lifestyle, experiencing recurrent crises, a poor sense of the what the service offers and the purpose etc. - For people with an intellectual and/or cognitive disability who have trauma histories and complex support needs, mainstream services struggle to respond adequately to their needs, which generally results in the person being punished and further traumatised eg: school expulsions, banned from services, child removals. - Where there is an intersection between trauma and intellectual or cognitive disability, often mainstream systems will only see the trauma and miss the disability. - We have observed many and frequent instances of direct and indirect discrimination against our constituents in mainstream services.
Interface between NDIS and Mainstream Systems	- There is a universal lack of understanding and implementation of the COAG Agreement. This exists across the NDIS from NDIA teams, planners, LACs, Plan Managers and Support Coordinators. - There is often a lack of agreement between the NDIS and Mainstream Systems regarding roles and responsibilities in supporting people with disability. Our staff spend considerable time clarifying who is responsible for helping our constituents in relation to NDIS vs Child Safety; NDIS vs Health; NDIS vs Justice Systems; and NDIS vs Education.

Structure	Problems and Concerns
	- The conflicts between these systems are seldom resolved. There is a lack of coordination and collaboration between systems. The fundamental needs of people with disability are treated as the problem not the failure of services to work together to address complex support needs.

Case Studies

All the NDIS participants in these case studies have given consent for them to be shared in this submission. Names have been changed to protect privacy.

System Interface: NDIS, Child Safety and Parents with an Intellectual Disability

Summary

This case study highlights the challenges faced by parents with intellectual disabilities who require support from the National Disability Insurance Scheme (NDIS) to access necessary services for parenting. Despite recognizing the need for parenting support, the NDIS system has not adequately provided funding for parents with intellectual disabilities, creating a gap between the child protection system and the NDIS.

Context

Parents with intellectual disabilities face unique challenges in navigating the child protection system, as they require tailored support to ensure that their disability does not impact their ability to parent. Community Living Association (CLA) is an organization that provides support to individuals facing complex challenges, including parents with intellectual disabilities.

What Happened?

The case study involves a parent with an intellectual disability whose child is in foster care. Child Safety recognized the need for parenting support for the parent to work toward reunification, and referred the case to the CLA's Parenting Support Team, which uses NDIS funding to provide tailored support for parents with intellectual disabilities. The team contacted the parent's Public Guardian (OPG) to obtain approval for using her NDIS plan for parenting support. However, the OPG responded that the funding should come from Child Safety and that they did not need to approve it. This created unnecessary delays and confusion for the parent, as the team had to go back and forth between stakeholders to determine how to access the NDIS funding for the required support.

What were the outcomes?

The NDIS's failure to recognize and adequately fund tailored parenting support for parents with intellectual disabilities has led to inadequate support for families in need. As a result, parents with intellectual disabilities often face barriers in accessing necessary support services, resulting in poor health and social outcomes. The lack of support from NDIS also leads to unnecessary delays in accessing critical services, further compounding the stress on parents.

Recommendations

To address this issue, the following recommendations are proposed:

1. The NDIS should recognize the need for tailored parenting support for parents with intellectual disabilities and adequately fund such services.

2. The child protection system and NDIS should work together to streamline the process of accessing necessary support services for parents with intellectual disabilities.

3. The NDIS should provide comprehensive assessments that capture the complex support needs of individuals with intellectual disabilities who require specific parenting support.

4. Stakeholders should prioritize joined-up approaches across systems to mitigate system failures and ensure that parents with intellectual disabilities receive adequate support.

System Interface: NDIS and the Justice System

Summary

NDIS reduces plan funding and does not offer continued support whilst young people are incarcerated. Adult Criminal Justice supports do not meet the disability specific needs of young people.

The NDIS states that they *"Can't fund supports (in correctional centres) that are more appropriately funded by other service systems such as the justice system".*

The Justice system provides help with personal care, disability related health supports and medical supports. The NDIS funds *Case coordination to "help you transition out of a justice setting, including the management of orders, child protection and family support, health, mental health, housing or homelessness services".*

Support Coordinators are unable to connect and build rapport with young people with intellectual disability and a trauma experience while incarcerated due to the nature of their role, need for relationship-based practice and the inability to be flexible and proactive due to the constraints of the role.

Context

Jack self-referred to ARROS as a young person with an intellectual and cognitive disability, with youth justice and out-of-home care experience. At the time of referral, Jack was not an NDIS participant, received no formal support and had minimal to no informal support. He was surrounded by people who used exploitation and violence, which resulted in engagement in criminalized activities. Throughout his time in ARROS, Jack has been transient and difficult to reach therefore requires workers to be flexible and proactive to develop a relationship.

Due to Jack's disability, trauma experience, and negative experience with other services, Jack requires considerable time to be spent building trust and rapport with him before he can engage with services. Jack requires workers to be proactive and flexible to meet his needs. Jack has difficulty linking actions to consequences and learning from experience. He also has limited impulse control and will act without understanding the consequences for his actions. This then leads to offending behaviours and cycles of incarceration. This in turn often leads to homelessness once released from (adult) prison as Jack has limited informal supports and is unable to sustain his tenancy whilst incarcerated.

This is a frequent cycle of incarceration and homelessness that Jack experiences and would be significantly reduced with increased NDIS supports while he is incarcerated to support him to attain housing, hold conversations with workers regarding offending behavior, and have his other disability support needs met.

What happened?

Jack was incarcerated in an adult prison, therefore his NDIS funding was cut despite advocacy for sustaining funding due to the disability supports in the prison system not meeting the needs of young people. Jack was needing support to attain suitable housing for when he was released, and had previously applied for both department of housing and social housing but was unsuccessful. CREST is a service within correctional facilities that can assist people in prison apply for housing and connecting to housing services. Jack has expressed to his ARROS workers that he is unable to engage with CREST workers while in prison. This is because Jack needs to talk to a guard in order to access CREST, however this causes Jack to be a target and puts him at further risk.

Young people find it difficult to engage in services connected to the prison system, due to trauma experienced within correctional facilities and restrictive practices used within these systems. These services do not use relationship based, trauma informed and disability specific practice, therefore young people like Jack are not able to consistently engage and have their needs met. Due to Jack's ADHD, Autism and Intellectual Disability, Jack can be agreeable and mask when he is unable to understand tasks and instructions set by workers young people has not built relationship and trust with. Services within correctional services often are often not able to be proactive and responsive due to the high number of inmates and nature of their role. Furthermore, CREST was unaware that Jack does not identify as having a disability and often cannot recognize his masking and identify his communication needs.

Due to NDIS funding being cut, Jack is unable to continue to engage with his therapeutic supports therefore he is unable to address the goals of his plan. Often services will only engage with young people like Jack once they are released, therefore by this point Jack is often already released into homelessness and into the cycle of offending and reincarceration.

What were the outcomes?

Due to the insufficient NDIS supports Jack received while incarcerated:

1. Jack was unable to find suitable housing to be released into. Therefore, Jack was released into secondary homelessness.

2. He had to live with the only informal supports he has, and the frequent offending, substance abuse, and violence within these relationships. A combination of this, and Jack's disability, continues to perpetuate the cycle of offending and incarceration.

3. He was unable access (skilled) NDIS workers to support him to understand his sentencing information, develop insight into his offending behaviors, substance use, and plan for support around this once released.

4. The inability of NDIS to support Jack's needs whilst incarcerated has led to homelessness, and his subsequent periods of remand/inability to access parole.

Recommendations

1. NDIS funding to remain the same when YP are incarcerated, to ensure young people like Jack have access to therapeutic supports & skilled workers relevant to their NDIS goals as defined in their plan.

2. Currently the NDIS *may* fund capacity building supports that will help young people when they're released, however their needs to be more push for funding for skilled workers (ARROS is a team of social workers) who have already built relationship and trust with young people. This will ensure continuity of supports and enable young people who are incarcerated to have access to disability specific therapeutic supports.

   This is more likely to have an impact on breaking the cycle of recidivism and reduce the cost to the system. It would improve his quality of life by addressing homelessness, violence, and substance use which will in turn hopefully reduce criminalisation.

System Interface: NDIS and Mental Health

Summary

The purpose of this case study is to demonstrate that NDIS is insufficiently funding psychological support for people with intellectual disabilities.

Context

NDIS participants with a primary disability of intellectual disability who also experience symptoms of depression and anxiety are being denied NDIS funding for psychology supports under Rule 5.1.b and s.31.4.f of the NDIS Act 2013, being that "support is related to participant's disability" and that it is "most appropriately funded by the NDIS and not be other general system or service delivery". As a result, participants with an intellectual disability are being required to utilise Mental Health Care Plans to obtain allied health (psychology) support for symptoms that are being overlooked as being directly related to their disability and impacting significantly on their daily functioning. According to federal government *principles to determine the responsibilities of the NDIS and other service systems* NDIS is the responsible funding body for "allied health and other therapy directly related to maintaining or managing a person's functional capacity including occupational therapy, speech pathology, physiotherapy, podiatry, and specialist behaviour interventions. This includes long term therapy/support directly related to the impact of a person's impairment/s on their functional capacity required to achieve incremental gains or to prevent functional decline". Planners are failing to consider the direct link between intellectual disability, mental health, and functional capacity.

What happened?

Fiona is a person with a primary disability of intellectual disability as well as a diagnosis of depression and anxiety. She is a person who thrives on social interaction, however because of her disability she faces significant barriers when attempting to establish relationships and opportunities for social inclusion. Fiona identifies as having no friends, and she experiences feelings of intense loneliness and social isolation.

Fiona lives alone and due to her disability finds decision-making and implementing helpful coping strategies difficult during times of low mood or stress. Fiona states that her low mood is caused by her feelings of loneliness and social exclusion. Her anxiety is related to her difficulty in making decisions and lack of access to the array of coping mechanisms that a person without an intellectual disability may possess or be able to learn with minimal therapeutic support. Fiona utilises accessible coping mechanisms in the form of addictive behaviours to alleviate her feelings of distress. As a result, her physical health and financial situation is significantly impacted. The coping behaviours ultimately exacerbate Fiona's depression and anxiety, as she struggles to process the impact of this on her overall quality of life.

Fiona's poor mental health is also directly related to her disability in that she has difficulty processing the steps required for aspects of daily living. An example of this occurred recently when Fiona's microwave stopped working. Unable to consider and process the options available to her when this occurred (for example, that she could utilise support time that day to purchase a new microwave, plan for a dinner that did not require use of microwave while planning/saving for a new one), Fiona called her CLP Social Worker in extreme distress, noting that she was experiencing suicide ideation as a result of this.

Fiona has a positive therapeutic relationship with a psychologist who provides in-home sessions and who has experience in working with people with disabilities. Fiona has expressed that she finds sessions with this psychologist helpful, and her preference would be to have these more regularly. During her previous plan period, Fiona had run out of funding for psychology sessions, and as at March 2023 Fiona has not seen her psychologist for approximately six months.

Fiona was recently supported to submit a change of circumstances form, which prompted an early plan review. The outcome of this plan review was that Fiona was denied additional funding for psychology sessions, with Rule 5.1.b and s.31.4.f being cited as the reason for this. Fiona's current NDIS funding allows for approximately six sessions of psychology per year. Fiona is not in a financial position to be able to privately fund sessions either in part or full.

What were the Outcomes?

Fiona has decided to utilise the NDIS funding currently available to her to fund six sessions with the psychologist with whom she has a long-term positive therapeutic relationship. Once she has exhausted this funding, the only option available to Fiona is to see her GP for a Mental Health Care Plan. Unfortunately, Fiona is unable to utilise this to fund sessions with her current psychologist. When Fiona is required to move to a Mental Health Care Plan, due to her financial situation, she will need to seek out a new psychologist who is able to provide no-gap sessions. The likely scenario is that Fiona will experience a significant wait-time before seeing a psychologist, at which time she will then utilise the bulk of her Mental Health Care Plan funding to establish a therapeutic relationship with the new provider, who may or may not have experience in working with people with intellectual disability.

The outcome of the NDIS limiting access to psychology supports for people with intellectual disability will be significant decline in people's functional capacity and overall wellbeing.

Recommendations

1. NDIS to recognise the direct correlation between intellectual disability, poor mental health, and declining functional capacity.

2. NDIS to provide appropriate funding to enable people with intellectual disability to access ongoing psychological support from experienced practitioners of their choice.

Complex Support Needs: Multiple Needs, Multiple Systems

Background

In late 2015, the Council of Australian Governments (COAG) agreed to a revised set of ‘Principles to Determine the Responsibilities of the NDIS and other Service Systems’. The Principles should be used to determine the service funding and delivery responsibilities of the NDIS vis-à-vis other service systems. In practice, the implementation of these principles has shown to be at best challenging, often inconsistent and in many circumstances non-existent. It is far from what the 6th principle proposes: “The interactions of people with disability with the NDIS and other service systems should be as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted, supported by a no wrong door approach.”

The following case study is just an example, among many, that aims to show how persistent incongruencies, inconsistencies and/or limited understanding about disability and the role of NDIS within the interface with other systems continue to negatively impact the life of many NDIS participants.

Context

Lisa is a young woman in her late 20’s living independently in a Department of Housing dwelling with her youngest son who is currently 3 years old. Lisa has two older daughters and another son who are in the care of Child Safety foster placements. Her life is largely determined by the frequent interactions with NDIS, Child Protection, Justice, Health, and Mental Health services.

In her early childhood, Lisa was assessed through the QLD education system as having a ‘Level 5 intellectual disability’ and having a ‘significant global developmental delay’. Due to her intellectual disability and low-level functioning in high school, she attended numerous special education units and schools. She was deemed eligible for disability services through the Dept of Communities & Disability Services in 2007.

Lisa also has a history of familial trauma. She has been subjected to sexual, physical, and emotional abuse. She was placed into foster care whereby she also experienced abuse during her foster placements. In her adult life, she has experienced severe domestic violence on multiple occasions from intimate partners. She was diagnosed in 2022 with Post-Traumatic Stress Disorder resulting from this long history of trauma and abuse.

The unfortunate and complex experiences that Lisa has faced in her life manifests in several issues such as difficulties with sleep, memories of past traumatic events, and rumination. Lisa has managed her emotional dysregulation with substances, largely cannabis and alcohol. In her adolescence she engaged in self-harm and aggressive behaviors, likely coping responses to her childhood trauma. She continues to struggle with managing perceived threats appropriately. Her presentations are representative of an insecure attachment style and trauma-based reactions which have developed over the years from childhood through adolescence. It also means that she does not have an informal network of support or reliable people to help with decision-making.

What is working?

Lisa started receiving support from NDIS in 2019. She is currently receiving support 5 days a week for domestic support, daily living activities and community access. She has also had access to counselling and psychological support.

The support received from NDIS has helped her to:

- Maintain full custody of her youngest son.
- Maintain her tenancy with Department of Housing.
- Ease daily living activities such as grocery shopping, lawn mowing, house cleaning, attending appointments.
- Engage in Counselling support which has opened a space to work on and develop practical parenting skills and strategies, understanding and applying knowledge or child development, building secure attachment with her children, emotional regulation and what is needed to be her best self to spend time with her children, and healthy and safe relationships for her as a parent and an individual.
- Engage in psychological treatment to address deficits in emotion regulation and interpersonal skills. These deficits are likely related to her childhood trauma and her cognitive impairment. She has been assisted to look at her attachment issues and trauma triggers. Additionally, how to identify pro-social peers and to disengage from relationships with potential negative outcomes or individuals who are likely to affect instability.
- Lisa has developed understanding around the importance of improving emotion regulation and interpersonal skills to be the best person and the best mother she can be, have effective interaction with the multiple services she is engaged with and to be able to consider working part-time which would go some way to building social relationships.

What is not working?

- The degree of childhood trauma together with the trauma experienced in her adult life, and more importantly, the intertwined impact of her disability and functional impairment have resulted in long-standing, entrenched patterns of behaviour that are provoked by trauma related triggers. Unfortunately, there is limited understanding within the NDIS and other services about the complexity of these interactions. In fact, NDIS is now challenging their responsibility to continue providing support for her PTSD disregarding the role of Lisa intellectual disability and developmental challenges in the magnitude of the manifestations of this condition. At the same time health and mental health services avoid any ongoing management and support for her as they allege that it is a responsibility of her NDIS supports or a matter to be addressed by private services that she cannot afford. In addition, the mental health services specialized in supporting people with intellectual disability offer very limited support as they indicated that they could not offer ongoing management. Managing her PTSD involves proper understanding of her disability and without this the support offered by NDIS will have very little positive impact.

- The complexity and long-lasting nature of her circumstances also imply that any actions or strategies to address her challenges will also need to be long lasting and ongoing to achieve the best outcome possible. The uncertainty in terms of responsibility from all the systems involved, implies that there is no ownership and commitment towards her case and often the funding and support is not adequate.

- The complexity and nature of Lisa conditions also imply recurrent crisis management which often involve a multisystem response: NDIS, criminal, legal, health and/or child protection services. Although NDIS has provided resources to respond to these types of events, the often inadequate and or ill-time response of other services result in retraumatising events and in responses that completely disregard the special needs linked to her disability. For example, the frequent and recurrent interaction with child protection services is in itself a triggering event due to the trauma experienced under their care. Their lack of trauma informed practices and the disregard of Lisa disability often result in escalations and interactions that in the in the end require police and legal involvement. These services also lack trauma informed practices and disregard the impact of the disability. As a result, a crisis that should not exist in the first place, evolves and escalates to a point that negatively impact Lisa life emotionally and physically, as well as her legal, financial and parental circumstances.

- In Lisa's case, her personal experiences in foster care strongly inform her anxiety about her children's foster placements and the way in which she initiates and responds to contact with Child Services. Compounded with her functional barriers, this has resulted in Lisa losing the custody of three of her children. Child protection services response has continuously disregarded their role in Lisa's trauma, have provided very limited support to address the challenges linked to her disability which should be part of any family reunification process, and have often used her disability as a way of justifying the actions taken against her. She has experienced harassment, abuse of power, lack of understanding of her disability, limited or absent support for parenting. Considering these circumstances, it is also disappointing that the NDIS has frequently challenged and denied their role in funding disability-specific parenting support.

- Police involvement has often been disproportionate and without regard to the complex psychosocial circumstances of Lisa. There is stigmatization and very small understanding of their role in triggering some of her challenging/coping behaviours. There are limited services and limited knowledge about the existing ones within the police department.

- For a long time, Lisa was not able to engage with Mental Health services due to their lack of trauma informed practices and the lack of a proactive approach. Now that she has developed enough skills to understand the potential benefits of this service through ongoing, consistent, and responsive support (from highly skilled disability specific supports), the public health system is turning their back and avoiding any involvement in the ongoing management of her condition. Private services are completely out of scope due to socioeconomic circumstances.

- Even though Department of Housing has provided her current dwelling, there has been a request for transfer for almost 3 years now. Her current residence was the actual place where many of the traumatic incidents of her adult life happened. It is a constant reminder and a trigger of her trauma history. It has also been discussed that Child Protection services and Department of Housing can and should work on a joint action plan to propose housing options, but to date it has not happened. Very confusing and inconsistent messages from the services involved are frequently given showing very little attempt for decisive action and disregard her disability. Although NDIS supports have helped Lisa to maintain her housing tenancy, there is no space available where "the interactions of people with disability with the NDIS and (Department of Housing) should be as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted, supported by a no wrong door approach" as proposed in the principles that underpin this case study.

Recommendations

1. The level of knowledge of understanding of NDIS officers around intellectual disability, psychosocial disability and trauma and the impact on people living with these conditions needs to improve. This would allow for the provision of appropriate funding for more developmental "walking alongside" responses that require skills, time, and proper funding for implementation. It would also allow for more flexible implementation of NDIS funding to address relevant issues such as crisis management.

2. The close connection between mental health conditions, intellectual disability and psychosocial disability implies that both systems - NDIS and mainstream health - need to develop spaces for joint action, for coordinated action and for recurrent interaction. They also need to provide flexibility and openness to address the real needs of those experiencing these conditions.

3. It is about time to formally review the implementation of the principles set up by COAG to determine the responsibilities of the NDIS and other service systems. This should lead to the development of tangible mechanisms that effectively and transparently action those principles. This implies for example, specialized officers or targeted projects within the different systems where direct communication between systems and joint action is possible to promptly and effectively address the needs of people with disability.

4. Marginalised groups have a historic mistrust of systems. Unless each service system develops their own mechanisms to respond to the special needs of these groups, and specifically of people with intellectual/cognitive disability, it is unrealistic to think that our society will enable them to fulfill their potential.

Complex Support Needs: Young People, Trauma and Social Disadvantage

Summary

The individual funding structure of NDIS results in rigidity of service provision and subsequent barriers for young people with complex support needs accessing services. Services that are funded by NDIS do not engage with young people that require relationship building to sign service agreements. This is due to their inability to bill for flexible and proactive supports.

Context

A significant number of people with intellectual disability will experience complex support needs in their life (ASID, 2019). Complex support needs are characterised by a combination of a person's breadth and depth of needs, involvement in multiple services, challenges in holistic and effective service response and changing needs over time, often during stress or crisis (ASID, 2019). The intersectionality between intellectual disability and complex support needs is not well recognised across sectors and impacts accessibility of services.

ARROS is a social work service (within CLA) that works with young people (15-24) with intellectual and/or cognitive disability who have experienced complex circumstances. They often have a history of trauma and social disadvantage which can result in complex behaviours that isolate them further from society.

Sarah is a 21-year-old woman who was referred to ARROS at age 16 by the Department of Child Safety, Youth and Women, to support Sarah with her transition to adulthood. When referred, Sarah's NDIS plan was inadequate. ARROS have provided extensive advocacy and practice coaching to support the increase of Sarah's NDIS plan. Sarah now receives social work support 4 days each week, however, has an underspent plan due to the inflexibility of the NDIS Pricing Arrangements and the subsequent impact on service provision.

What Happened?

Sarah has experienced significant support from statutory and community services. However, due to her cognitive and psychosocial disabilities, she has found it challenging to maintain these relationships. She requires support services to be proactive and flexible in their approach and responds best to a relationship-based model. Due to the prevalence of dysregulated behaviors, and exposure to risk, services have found they are unable to work with Sarah due to the physical and emotional risk to workers. ARROS have been able to mitigate this risk by only offering Social Work or equivalent skill level, implementing a two-worker model, having safety plans, and workers having access to regular supervision. This has only been possible because of the block funding ARROS receives for other programs from the State Government ie: block funding offsets the losses we incur from the NDIS funding model. Providers relying on NDIS individual funding are unable to be flexible and proactive without operating at a loss. This results in Sarah being excluded because the relationship building phase can be inconsistent.

During a period of disengagement, crisis, and transience, Sarah's Support Coordinator changed due to staff turnover. Sarah's dysregulation meant it was extremely difficult for her to connect with a new Support Coordinator. ARROS supported this change by providing practice coaching to the new Support Coordinator about Sarah's support needs during cycles of crisis.

Sarah's Service Agreement with her Support Coordinator lapsed during the peak of crisis and Sarah was told they were unable to provide any support without a signed Service Agreement. After processing this with Sarah, she agreed to connect with her new Support Coordinator face to face to sign the agreement. Despite the clear importance of a Service Agreement for continuing support, the Support Coordinator was unable to provide any flexible or proactive support to get it signed. ARROS needed to provide further practice coaching to the new Support Coordinator about Sarah's disability support needs to process and understand the service agreement. The Support Coordinator, however, said they were unable to meet with Sarah as they were unable to bill that time without a signed Service Agreement. ARROS tried to support Sarah to sign the agreement without the support of the Support Coordinator, but Sarah was experiencing acute crisis and needed to prioritise ARROS outreach for crisis response. The Support Coordination service decided to exit Sarah.

Outcomes

Sarah was unable to sign the Service Agreement and due to the barriers she faced in reconnecting, the relationship ruptured. The Support Coordinator was unable to rebuild relationship without a Service Agreement and Sarah was unable to sign a Service Agreement until the service had rebuilt the relationship. For five months, ARROS have been supporting Sarah to try and connect with a new Support Coordinator. Sarah currently has no Support Coordinator.

Sarah continues to face barriers to accessing her plan due to services unable to offer flexibility within NDIS' funding structure. Sarah's plan is underspent due to the inflexibility of service provision, despite Sarah having a high level of support needs.

Recommendations

1. People receiving NDIS funding would benefit from a mix of individual and block funding to allow for more flexibility in service provision. This would be especially beneficial to people with complex support needs that require an individualised, relationship-based case management approach alongside more skilled workers whose remuneration levels aren't reflected or covered by NDIS' Pricing Arrangements.

Complex Support Needs: Intellectual Disability and Mental Health

Overview

- Tom has complex support needs and comorbidities which are not recognized or properly supported by NDIS.
- The deficit model of NDIS can be triggering for Tom, and lack of insight makes seeking support challenging for him.
- Review processes lack transparency and require significant follow-up if rejected, which creates additional strain on already stretched funding.
- Supports are spread across different agencies and organisations with varying skill sets and values bases. It is difficult to coordinate supports and ensure supports are constructive.

What's working?

For Tom:
- Receiving and engaging in support to access community and additional services (food hampers, health, etc).
- Daily living/domestic support (cleaning, cooking).
- Linked with mental health counselling through NDIS funding.
- Receiving support coordination.
- Able to choose supports who feel like a "good fit" and feel safe.

What's not working?

- Tom doesn't have enough funding to support the achievement of his goals and respond to his complex support needs.
- Tom seeks meaning and belonging in online communities that present significant risks to Tom. Skilled workers with a professional knowledge base and therapeutic skill set who are able to challenge Tom when required for his safety, whilst being able to maintain a relationship with him.
- Support Coordinators can be too busy and not accessible enough.
- Tom's disability is not visible to many, and he requires more support than what is immediately apparent, due to his masking and presentation.

- The deficit focused model of NDIS Planning Meetings and the requirement for participants to self-articulate their functional limitations and needs doesn't take into consideration trauma, masking, or lack of/barriers to insight.
- NDIS Planning meetings have failed to consider other co-related issues (MH, sleep disturbance) that intersect with disability and compound Tom's functional limitations.
- The NDIS funding model doesn't allow for communication and coordination of supports across the multiple organizations involved in Tom's supports, ie: coordination and communication is concentrated in one individual/role (Support Coordinator), versus allowing for organisations who support Tom engage, communicate and plan together in a holistic fashion.
- No value is placed on the reports/advocacy from Tom's Social Workers by NDIS.
- There has been a lack of transparency from NDIS when requests for review(s) from Tom have been rejected.
- Tom has significant out of pocket costs for support related to his health/disability (sleep, routine, exercise).

Recommendations

1. Funding reviews should be more transparent. Seeking clarification of a rejection or reduction in funding should not require an FOI application.

2. More thorough assessment processes and greater weighting of reports and information from GPs, Social Workers, and Mental Health therapists – those with longstanding relationships and more detailed knowledge of the needs and capacities of the NDIS participant.

3. Additional/dedicated funding for inter-organisational collaboration and communication.

4. Improved framework around complexity and links between various conditions. There is an intersection between mental health and a person's intellectual and/or cognitive disability that can compound impairment(s). If a participant's mental health is poor, general functioning is reduced, and more support is required.

5. Disabilities are not necessarily static, and an individual's intellectual disability related challenges/barriers can fluctuate with mental and physical health.

Complex Support Needs: Family Units

The NDIS is not an effective system for complex families.

Context

- A family is:
    - At least 1 parent, and
    - A child or children under 18y.o

- A complex family is:
    - Where 2 or more people in the family are NDIS participants, and
    - At least 1 of the participants has their own complex support needs.

What's Not Working?

- Parental responsibility is being weaponized as a means to deny supports, without consideration of what is humanly possible in the whole of family context.

- There is no flexibility in funding to accommodate the ebb and flows of family or consider the interconnectedness of families. For example, if something happens with one family member, that may disrupt the support needs of other family members – however this is not considered when plans are created.

- Multiple planning meetings, i.e. each member of the family have their own meeting disregarding the context of other family members.

- Planners have little understanding of the importance of respite (STA). It is often not considered in the whole family context.

- School holidays present a stressful time where extra supports are required, but this is often not funded. Furthermore, service providers find it difficult to provide a surge workforce for these set periods of time.

- Navigating and negotiating with the NDIS creates an extra point of stress for families that are often already at, or beyond, their stress limits.

Recommendations

1. NDIS should consider implementing creative and flexible family driven solutions to support the needs of complex families.

This could include:
    - Block funding for some of the family's support needs to be used flexibly across the family.
    - Joint Planning meeting to better coordinate funding across the family
    - Finding mechanisms to support organisations to retain staff needed for school holiday support.

2. If one member of the family is managed through the NDIS Complex Support Needs team, then the whole family should be coordinated through that team.

3. NDIS Planners and Internal Review Staff need to consider and act on Allied Health recommendations.

4. Complex Families require Specialist Support Coordination.

Complex Support Needs: Recognise and Fund Micro-Enterprises in Employment Supports

Context

The NDIS is not appropriately funding reasonable and necessary supports for people with complex support needs to establish and maintain their micro-enterprises.

There is an assumption within NDIS that there is either an informal support network who are providing unpaid support in this endeavor or that support for a micro-enterprise can be undertaken through 'usual' support worker functions.

The NDIS are aware of Micro-Enterprises. There has been a community awareness campaign and 'Discover Micro Enterprise – Exploring the Possibilities Project' is funded through an Information, Linkages and Capacity Building (ILC) grant with the Department of Social Services (DSS). NDIS participants were supported to build their own small businesses, tailored to their individual talents, passions, and needs.

What's Not Working?

- Decision Makers- Planners/Internal Review Staff are not aware of or understand micro-enterprises and the supports they require to establish and sustain them.
- Non face to face support or Capacity Building Employment support is not being provided to these participants to develop and sustain their microenterprises.
- On the one hand, a lack of understanding of participants and how a micro-enterprise can be vital to good mental health and having a meaningful role in the community. On the other hand, aspects of the micro-enterprise can be significantly detrimental to participants' mental health and need to be supported separately to the participant (i.e. non face to face support). For example – a participant who has delusions about being a millionaire and gets fixated and distressed about money – cannot participate in the financial aspects of a microenterprise for risk of worsening mental health.
- Lack of understanding by Planners/Internal Review Staff about ancillary costs and geographic difficulties. Most micro-enterprises are not financially self-sustaining, this is especially true if transport is involved.
- Participants are being de-funded from their 1:1 support needed to undertake their micro-enterprise, which means they either need to end their valued role as a micro-enterprise business owner or go through the stressful review process.

Recommendations

1. NDIS Planners and Internal Review Staff be trained to understand a micro-enterprise is part of employment and requires employment support.
2. NDIS needs to fund the discovery phase of a micro-enterprise as recommended by the ILC micro-enterprise project.
3. NDIS Planners and Internal Review Staff need to consider and act on Allied Health recommendations in relation to micro-enterprises.

Complex Support Needs: Unrecognized and Unmet Needs #1

Summary

NDIS is not an effective system for people with complex support needs, i.e. dual disabilities, aging parents.

Context

Connor is a 48-year-old male. He is diagnosed with Autism Spectrum Disorder (Level 2), Paranoid Schizophrenia, Borderline premorbid functioning, F71 Intellectual Developmental Disorder of Moderate Severity (FSIQ 56 – Exceptionally low score). His Functional Capacity is assessed by his Clinical Neuropsychologist and OT to be equivalent to a child aged nine years or lower. Connor's only informal support is his mother, who is 75 years old, a widow and with chronic health conditions.

Connor should be recognised as having complex support needs under NDIS. However, Connor's file remains with the Local Area Coordinator (LAC) at Carers Queensland. This also results in information that is shared in the plan review meetings with the LAC not being transferred or shared with the NDIS delegate who drafts and reviews Connor's NDIS plans.

Connor has lived alone for over 20 years. This is his decision - to live on his own and have his own space. His mother lives 45km away from him. Before NDIS, his mother had to travel 2 hours return every day to support Connor with his daily living tasks. With her advancing age and declining health, she is no longer able to meet Connor's intensive disability needs.

Connor was assessed by two Occupational Therapists, a Clinical Neuropsychologist, a Psychiatrist, and a Mental Health Case Manager from the hospital. Their assessments consistently state that Connor needs 12 hours of disability specific in-home and community access support per day. Connor has complex disability support needs, but NDIA refuses to meet those needs.

What's Not Working?

Since 2021, Connor and his family have been in a battle with the NDIA as they have deemed Connor ineligible for the requested hours of support. The family has put in several Change of Circumstances requests with multiple supporting documents from Allied Health Professionals with consistent assessments and recommendations. In both plan review meetings, Connor and his family have clearly articulated Connor's goals and support needs. However, the NDIS delegates did not consider Connor's choice and control, and all the professional assessments, when building his NDIS plans.

Based on the plan review meeting interaction notes requested via Freedom of Information, both Connor's NDIS plans are built based on the expectation that Connor's functional capacity will increase, he will continue receiving informal support from his mother, he will attend social groups, and that he only needs prompting to complete most daily living tasks. These are all inaccurate statements and in direct opposition to the evidence submitted to the NDIA.

This will be the third time the family is challenging a NDIA decision using the same supporting evidence that they have already submitted. The NDIA is breaching Connor's basic human rights to choose who he wants to live with and where he wants to live, breaching their own legislation by refusing to provide reasonable and necessary disability supports, and ignoring Allied Health professionals' assessments and recommendations. The importance of the latter has already been acknowledged in AAT cases. Alongside the impact on Connor, is the impact this is having on his elderly mother. It is causing her tremendous distress.

Based on this case, the NDIA is not competent to assess complex support needs. It does not have planners and delegates with the skill and knowledge to recognise and respond appropriately within legislative guidelines, including appropriately streaming participants. If NDIS funded Connor based on his reasonable and necessary support needs, as articulated in 5 separate allied health reports, Connor's support team could implement their skillset and expertise in supporting Connor to live a meaningful and satisfying life, and to explore capacity building opportunities. Instead, time and funding is being wasted going back and forth gathering and writing reports that state the same thing repeatedly to the NDIA, who are refusing to recognise and respond to the evidence presented to them.

Recommendations

1. NDIS Planners need to have the skill and knowledge to recognise and respond appropriately to different types of disabilities and complexities.

2. NDIS Planners should have to clearly justify when and why they do not follow the recommendations of Allied Health Reports, with commensurate levels of expertise and evidence.

3. The NDIS should have clear, fair, transparent, and timely processes in response to plan review requests.

4. The AAT process should not be the only avenue for external and/or independent reviews for NDIS decisions.

Complex Support Needs: Unrecognized and Unmet Needs #2

Summary

NDIS is not an effective system for people with complex support needs.

Context

- Jill has an intellectual disability co-occurring with psychosocial disability i.e., anxiety and hoarding disorder.
- CLA provides therapeutic, social work support via a trauma-informed, strengths-based and relationship-based perspective. This also involves supporting the individual's capacity to process information, regulating her feelings and emotions, planning and problem-solving, and setting goals.

What Happened?

CLA's experience of supporting Jill:

- Jill does not have strong informal network of supports or people to help with decision-making. Due to past traumatic experiences, Jill has a high level of mistrust when it comes to meeting new people and forming new friendships and relationships. (This is at odds with the NDIS framework).
- Jill does not have interactions with many systems and is extremely socially isolated.

- Jill experiences persistent difficulty and distress in discarding possessions and struggles with impulsive purchasing of items, which subsequently impacts on Jill's health, well-being, relationships and living environment where her tenancy and safety is at risk.
- Due to previous experiences of betrayal and fractured friendship and relationships, Jill takes a very long time (i.e., several months to a year) before sharing those experiences.
- Functional Assessment reports written by social workers are not valued by planners despite the amount of time that social workers dedicate to supporting and working with the Jill.
- During plan review, Jill's initial request for a two-year plan was rejected due to the amount of capacity building funding requested. Consequently, Jill was granted a one-year plan with additional capacity building funding, with the expectation that several outcomes would be met within that year so the Jill's funding could subsequently be reduced.
- NDIS's perspective seems to be that change and growth are a linear process. There appears to be a mismatch in NDIS's concepts of permanency and stability with the fluctuating nature of mental and physical health – more so for individuals with complex support needs. NDIS plans do not take into account the changes and fluctuations in people's lives.

What were the outcomes?

- Poor health and social outcomes.
- Jill must go through plan reviews multiple times, and to sit in a space of discomfort whilst experiencing a sense of embarrassment, especially speaking with someone who is completely foreign and unfamiliar talking about her needs and challenges.
- Extra supervision supports are required for workers responding to complex support needs and NDIS doesn't fund this adequately.
- CLA social workers often have to engage in practice coaching with other workers to ensure better outcomes for constituents.
- NDIS "dumbs down" what support work with this group looks like. It requires skilled, qualified practitioners. This does not fit within NDIS' model of 'disability support workers'.
- A one-year plan with the purpose of establishing immediate outcomes indicated to Jill that there has not been much growth and progress over the past few years, which perpetuates her sense of low self-esteem and confidence.

Recommendations

1. A mix of individual and block funding will allow for a better response for people with complex support needs.

2. Flexibility in NDIS plans in relation to adequately and effectively responding to Jill's complex needs.

3. NDIS to provide training for planners about different types of disabilities and different needs, as well as to include regular professional development.

Complex Support Needs: Cutting Funding and Inaccessible Processes

Summary

The NDIS is not transparent about reason for rejected applications or reduced funding; and internal request for information process is inefficient and not responsive to participant's needs.

Amelia's NDIS funding was cut with no reasons given. Request of internal review failed and required several attempts of follow up to get a response after months.

Context

- Amelia has an intellectual disability and has experienced complex trauma in her life.
- She wanted to maintain her employment and continue having support for work.
- Amelia received new plan in Sep 2021 since the previous one expired. The funding was cut but no reasons were provided.

What Happened?

- Amelia reported that before her NDIS plan expired, someone from NDIS rang her checking how everything is going. She was told by the caller that her NDIS plan would remain the same.
- However, when she received her new plan, her 'Finding and Keeping a Job' funding was cut significantly, and Amelia was not aware of the reason.
- A social worker supported Amelia to submit internal review request in Dec 2021. They had received no response by March 2022, despite the official guideline stating the usual response time frame would be 60 days.

- The social worker rang the NDIS in March 2022 to follow up and was told that the request was still being process.

- The social worker followed up again in May 2022 and was told the participant needs to submit a consent form for the social worker to be able to submit an enquiry about Amelia's plan. The social worker was also informed that the request was not able to be processed as it was not submitted by the participant herself. This information was not provided by anyone in the review request process including in any of the previous follow-up phone calls.

- The social worker was advised the only way forward was for the participant was to submit another internal review request.

What were the outcomes?

- Amelia has insufficient funding for support at work, and she has been unable to sustain her employment.
- Amelia has insufficient funding to meet her increased need for support in health management of a chronic health condition.

- Insufficient funding and gaps in support has resulted in Amelia being unable to attend work and having less income. As a result, the participant has experienced increased stress, isolation, and a decline in her mental health (increased anxiety).

Recommendations

1. The NDIS should acknowledge and respond to the difficulties and challenges people with intellectual disability and complex trauma history face in communicating with NDIS.

2. The NDIS should provide participants with clear reasons for the decisions made about their plan, including clear reasons why funding is cut.

3. The NDIS should be transparent in the review process and inform the participant of all necessary information at the earliest opportunity (i.e. inform the participant that the request was not able to be processed once they identified this issue rather than just overlooked it).

Problems with Planning Processes and Reviews: Lack of knowledge of intellectual disability

Summary

NDIS planning meetings are not effective for people with disabilities that are not physical or visible and who use masking behaviours to hide their disability.

Context

Declan is a man in his forties who has multiple diagnoses:
- Schizophrenia
- Intellectual Disability
- ADHD
- Addiction (alcohol and gambling)

Declan demonstrates the following:
- No physical or visible disability
- Does not identify with the language of “having a disability” and is able to mask at a high level especially during NDIS planning meetings.

What happened?

The NDIS system does not meet Declan’s needs:
- The system is geared towards physical and visible disabilities, not invisible disabilities which can be masked like Declan’s.
- NDIS planners ask closed questions. Due to Declan’s tendency to be agreeable, his complex support needs are not recognised during NDIS planning meetings.

- Declan's masking behaviours result in inaccurate assessments of his needs by NDIS planners. The true complexity of his case is overlooked as he presents well and is agreeable.

Declan receives insufficient funding for his support needs:
- He struggles to break the cycle of addiction and build his capacity.
- He experiences a lack of stability in his work and daily life.

Recommendations

The NDIS should:

1. Recognise the value of certain formal relationships in participant's lives, and if the participant consents or requests it, listen to their perspectives. This is particularly important when a person's disability is not readily visible or observable.
2. Have Planners knowledgeable and skilled in intellectual and/or cognitive disability, including an understanding and awareness of masking and acquiescence.

Problems with Planning Processes and Reviews: A series of injustices

Summary

The NDIS internal and external review is ineffective, inefficient, and unjust.

Context

A participant with a rare neurological disability seeks 24/7 1:1 core support due to a significant decline in her functional capacity.

In May 2022, the participant submitted all supporting documents and evidence from her treating team as part of her plan reassessment meeting.

The request was declined by the Home and Living Team in July 2022. The participant, with support from her elderly mother, submitted an internal review request as they were not satisfied with the decision justification, which was a single paragraph quoting s34 of the NDIS Act without elaborating on how those related to her individual situation. In November 2022, the internal review team informed the participant that the original decision stands. Whilst the internal review team provided additional details of their decision, the participant and her mother found several statements intimidating and humiliating as they were made without objective and rational explanations.

The participant and her mother decided to apply to the Administrative Appeals Tribunal (AAT) for an external review. They asked the Support Coordinator to provide information about, and referral support, to connect and link to mainstream legal representation options and independent disability advocacy services.

What Happened?

The participant and her mother were disappointed and frustrated when the initial Home and Living Request was declined as no one from the Home and Living team attended the plan reassessment meeting. Further, the delegate (planner) who met with the participant had no influence on the Home and Living Decision.

The participant and her mother also felt helpless and overwhelmed at the prospect of needing to self-represent at the AAT as neither Legal Aid nor any Non-legal Advocacy Organisations had the capacity and availability to represent her free of charge.

The participant was not allowed to use her NDIS funding to pay for a lawyer, Support Coordinator, or a service provider to represent her. She is on the Disability Support Pension with limited disposable income. Due to her disability and complex trauma, she is unable to represent herself at the case conference. This means her elderly mother needs to step in and advocate for her daughter with very limited knowledge and understanding of the NDIS Act and AAT process.

The Support Coordinator is aware of how fragile and isolated the family is as she has been working alongside the family for over ten years (as a Social Worker and now a Support Coordinator). The Support Coordinator feels compelled to assist as the injustice is so great that she is unable to stand by and do nothing. With the organisation's authorisation, the Support Coordinator is able to aide in the AAT process pro-bono ie: unfunded work in a separate role.

Eventually, the Support Coordinator manages to find a private lawyer who specialises in NDIS Appeals and has a strong passion in human rights, social justice and working with vulnerable families. Through extensive conversations, the lawyer agrees to represent the participant at a reduced rate, which is a huge relief to the participant and her mother. The mother was prepared to, and was going to need to, refinance the family home to pay for the legal fees. On the eve of the first case conference (Jan 2023), the participant's mother was approached by the NDIA AAT Case Manager and the NDIA Lawyer, asking her to vacate and relist the case conference as 'the Agency is still awaiting a response from the Home and Living Team on the request of 24/7 1:1 Support'. This was completely unethical and should be regarded as an act of intimidation as both the Agency Case Manager and the Lawyer were aware that the participant has legal representation.

In Feb 2023, the Agency provided their first Statement of Issue to confirm the request for 24/7 1:1 core support is reasonable and necessary for the purpose of the NDIS Act Section 34(1). The position was made without requesting the participant to provide additional evidence.

A week later, the participant received the 42C Terms of Agreement with 24/7 1:1 core support. The NDIA overturned their original decision that was made back in May 2022.

If the Home and Living Team had done its due diligence by meeting the participant at the plan reassessment meeting and reviewing all supporting documents and reports thoroughly before making a decision, the participant and her family would not have to go through such a daunting and inhumane process.

This also highlights how cost-ineffective and unjust the AAT process is for the majority of NDIS participants. The NDIA is represented by lawyers who are funded through taxpayers' money whereas vulnerable NDIS participants need to either:

1) Self represent;
2) Plead their case to those chronically underfunded Legal Centres and Non-Legal Advocacy organisations; or

3) Sacrifice their basic needs / family home to pay for a private lawyer.

Recommendations

1. A delegate from the Home and Living Team needs to be present at the plan reassessment meeting. They need to make a decision not just based on reading reports and supporting documents remotely, but to actively engage in the planning process with the participant and their supporters.
2. There needs to be a clear framework and guidelines on how the Home and Living Team operates.
3. A contact phone number and email for the Home and Living Team needs to be included in the participant's plan.
4. There needs to be more funding for disability advocacy organisations and legal centres where advocacy support is accessible and affordable for those who do not have the means to pay for a private lawyer.
5. If a participant engages in the AAT review process, free counselling and support services need to be made available for them and their supporters. The stress, fear, trauma, and intimidation they experience in this process is excruciating.

The Importance of Support Coordination: Unfair expectations of informal supports

Overview

Mark is a young man living with his family in the Moreton Bay region. Mark has multiple diagnoses (ASD; Intellectual Disability; Treatment Resistant Epilepsy; Treatment Resistant Depression; Hearing Loss; Osteoarthritis) which create a need for near-constant support, particularly due to risks posed by his epilepsy.

Mark's current NDIS funding is not sufficient to meet his plan goals or to maintain his current quality of life. Mark's independence is currently limited due to insufficient funding to engage with formal supports. Mark has never received funding for Support Coordination, so plan implementation and accessing services has always been handled by his mother. His informal supports are limited in their capacity to meet Mark's support needs.

What is working?

- Mark is currently receiving support in employment and capacity building, however funding is not sufficient to maintain supports.
- Mark is able to engage in some activities with support.

What isn't working?

- No Support Coordination at early stages of NDIS engagement. Currently held by family member who says they do not have the knowledge/skill to support access to other services.
- Plans rolled over without review, therefore no additional information or change of circumstances has been considered in new plans. Insufficient funding for support towards goals.
- Services feel they must act within constraints of funding, rather than supporting the family to advocate for an increase in funding and plan reviews.

- Mark generally appears to have higher capacity than he actually does. He masks in conversations (e.g. will just agree without asking questions), making it difficult for others to gauge his actual understanding. Mark's disability is not "visible enough" for accurate recognition of his support needs by the NDIS.
- There is not enough consideration of the support Mark needs to manage his additional health issues (epilepsy, mental health etc), and the intersection of these health issues with his disabilities.

Recommendations

1. Support Coordination for all participants who request it, similar to Plan Management.

2. Review the role played by assessments in the NDIS Planning Process, and the knowledge the person doing the assessment has of the participant. Assessments can be avoided by people with an intellectual and/or cognitive due to being arduous and challenging. Without knowledge of the person, assessors can also fail to observe masking and concurrence.

3. It should be possible for new information or reports to be considered and responded to by NDIS without having to require a full plan review process.

4. Increase communication around NDIS plan reviews and roll-overs of plans – what is going to happen and when, what information can and should be shared from the NDIS and Planner.

5. An improved framework around complexity which understands the links between various life circumstances, experiences, and areas of wellbeing with the person's disability(s) and functional capacity.

The Importance of Support Coordination: NDIS is too complex.

Summary

The NDIS is too complex for many Participants to implement their plan without Support Coordination or other support.

Context

Many Participants do not receive Support Coordination in their initial plan and do not have capacity themselves, or available and capable informal supports, to implement their plan. They receive information from an LAC regarding what supports and services to make contact within the disability and mainstream services sector. This sends many participants and their families on a lengthy and burdensome path to try and find appropriate supports with service capacity. Worker turnover and other change in circumstances then often lead to participants needing to revisit this process over and over with lapses in support and the multiplication of intake processes leaving people burnt out and disempowered.

What's not working?

- Participants without Support Coordination trying to navigate the NDIS system to implement their plans without meaningful support. Confusion regarding 'first steps' of plan implementation, significant amounts of time and resources spent contacting providers, completing intake/referral processes, waiting on waitlists etc which may not lead to receiving supports and services.

- The system is too complex. Participants are often misinformed by existing supports such as mainstream Health, Support Workers or Allied Health regarding how to navigate it.

- Participants who experience Change of Circumstances and no longer have capacity to access and coordinate their supports overwhelmed by process of Change of Circumstances for Plan Review and no tangible support given other than direction to NDIS website forms and resources.

- Long wait times for outcomes of NDIS processes; NDIS not responding with action in timeframes outlined in Participant Service Guarantee.

- Fatigue, stress and impacts to health and wellbeing from trying to implement plan after what may have been a complex and time-consuming process to access the scheme.

- Plans underutilised and necessary support not received.

- No follow up with Participants who aren't implementing plan until plan review date.

- Disengagement from scheme.

Recommendations

1. Support Coordination for all participants who request it, similar to Plan Management.

2. Process of monitoring plan usage and identifying plan utilisation issues.

3. Simpler processes for additional Support Coordination funding to be accessed when needed, potentially drawn from Core.

4. Combination of individual and block funding to allow for more flexible response to funding issues.

5. Planners and LACs better resourced and skilled to meaningfully assist participants' access to supports and implement their plans – more than just directing them to where they can find information or request support, needs a 'walking alongside' approach.

Appendix: The Intersection between Intellectual/Cognitive Disability and Trauma

Trauma & Attachment

Trauma Histories, particularly Complex or Developmental Trauma

Many of the people we support have significant trauma histories and have experienced a high number of 'Adverse Childhood Experiences' (ACEs). This includes childhood abuse and neglect, sexual abuse, domestic and family violence, and institutionalization.

Their trauma intersects with their intellectual and/cognitive disability(s) to significantly reduce their functional capacity.

Trauma and attachment responses and needs we see in our work include:

- Difficulty building or maintaining relationships, both formal and informal
- Difficulties empathising
- Low distress tolerance
- Low impulse control and inhibition
- Deflection onto others
- Attempts to exercise control over their environment, including other people.

- A push/pull engagement style.
- Being in unsafe relationships.
- Being exploited, and/or exploiting others.
- Limited understanding of safe and healthy relationships.
- Testing, or over-stepping, other people's boundaries.

- Frequent escalations
- Sustained escalations
- Harm to self and others
- Aggression, both verbal and physical
- Property damage
- Threats

- A history of criminalisation, and/or ongoing risk of criminalisation.
- Coping strategies that involve desensitising from the trauma, for example engaging in substance use to numb emotional and psychological pain.

- Limited, or no, informal supports.

Recurrent Crises

Many of the people we support also experience recurrent crises related to the following issues:

- Peer violence and threats of violence
- Domestic and Family Violence
- Intention to commit violence
- Mental health and suicidality
- Substance use and safety eg: overdose risks, unsafe environments
- Homelessness – either being at immediate risk or real experiences eg: sleeping on the streets
- Significant injuries
- Presentations to hospitals

The Experiences of People with Complex Needs of Other Systems and Providers

When unable to receive adequate and skilled support, being banned or having their access restricted to:

- Mainstream systems such as Services Australia and the Department of Housing
- Employment agencies (mainstream and disability specific)
- Workplaces (mainstream and disability specific)
- Multiple Doctor’s surgeries
- Shopping centres
- NDIS providers
- Community supports, such as those provided by other NGO’s.

NDIS services exiting or withdrawing for reasons including:

- Organisational risk assessments.
- Workers being unwilling to work with people due to the level of risk involved (real or perceived).
- No therapeutic gain: the participant is unwilling to engage in the therapeutic process.
- The participant disengaged.
- Frequent presentations at NDIS services causing safety and capacity issues for providers eg: multiple phone calls a day, presenting at offices daily, immediate escalations if not responded to.
- The intensity of the work: trauma and attachment responses are frequent eg: a worker may say something that doesn’t align with the person’s thinking, or may gently challenge them, leading to a high-level escalation, and this can happen frequently.
- The flexibility required: having workers available to respond when the person needs support; being able to offer pro-active outreach to build relationship and meet immediate needs.
- The skill required: the service doesn’t have appropriately skilled workers.

Participants exiting services for reasons including:

- A high level of conflict.
- An inability to build or hold a relationship.
- Their needs and/or goals aren’t met.

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