COMMUNITY LIVING ASSOCIATION
ABN: 51 989 937 672. NDIS ID: 4-4331-924
Community Living Association
Growing communities where all people are valued
5 Nundah Street, Nundah QLD 4012 Phone: 07 3266 5633 www.communityliving.org.au
Coordinator: tlawrie@communityliving.org.au **Enquiries:** reception@communityliving.org.au

NDIS Review Submission – Part 2

The Views of CLA Participants, their Parents, and Informal Supporters

Dear NDIS Review Panel,

This submission to the NDIS Review Panel presents the views of:

- People with intellectual and cognitive disability who are NDIS participants supported by CLA, and
- Family members and informal supporter(s) of NDIS participants supported by CLA

Community Living Association

Community Living Association Inc. (CLA) is a community organisation based in Brisbane North that supports people with intellectual/cognitive disability. CLA are a registered NDIS provider and provide a range of supports including Allied Health, Core supports, Groups, Support Coordination and Plan Management.

CLA was established in 1989 as an Independent Living Service for people with intellectual disabilities. CLA currently operates five services and works with people with intellectual/cognitive disability (constituents) who are:

- Homeless or at risk of homelessness,
- Young people with a Child Safety and/or Youth Justice experience,
- Parents, and/or
- Experience co-occurring psycho-social disability.

CLA practice and services have developed from the issues raised by the CLA constituency, including experiences of trauma, mental health, addiction, substance use, criminal justice, Child Safety, physical health and wellbeing, and money management.

CLA constituents and their significant others 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.

NDIS Review Project

CLA commenced the NDIS Review Project in March 2023 to support CLA constituents and their supporters to contribute their views and experiences of the NDIS to the NDIS Review. CLA constituents and supporters were recruited to the Project from CLA services - Community Living Program (CLP), CLA Support Coordination and ARROS - to have a say about their experiences of the NDIS.

The NDIS Review Project Worker conducted informal in-depth interviews with 26 respondents:

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- 18 constituents with intellectual/cognitive disability who are NDIS participants
- 8 parents or supporters of NDIS participants
- Interviews were conducted face to face or via telephone or email
- Confidentiality was discussed at the start of all interviews and no identifying names or information has been shared.
- All respondents provided consent for their views to be shared to the NDIS Review.

Sincerely,



CEO / Coordinator
CLA Inc.

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Views of NDIS Participants

The following section is a summary of interviews that were conducted by CLA of NDIS participants we support. Eighteen people were interviewed in total. Informed consent was obtained to include their views in this submission, and people have been de-identified.

It is noted that interview respondents represent a small sample of total CLA constituents. Their views and experiences may not be representative of other constituents who were not able to participate in this process due to barriers presented by complex disadvantage and social marginalisation.

What is good about the NDIS? What are things you like about it?

Access to Supports

"NDIS funding helped me find a SIL that is a safe and appropriate place".

"With the funding I can purchase and maintain assistive care items such walker, walking stick, exercise bike, railing on my flat to help with daily lives. Without the associated care stuff, there's no way I would get involved in the activities that I like to do. Access to associated care stuff makes other things possible".

"Enables me to get and do the things that I wouldn't be able to get by myself. They funded me a scooter 2yrs ago. OT assessment to be able to get the scooter and have to do the same to get my bed and recliner. Happy with those assistive technology/things".

"I have what I need, and it covers everything I need."

"Makes medical treatment accessible and stuff like physio, psychology all the allied health services".

"Happy with my plan: involved in CLP activities such as NAS, adventure group and speaker groups; socialisation, community access".

"It also allows to attend groups that CLA have e.g. scammers, adventure and some role part of CLA committee as treasurer and being involved in housing group as treasurer".

"Happy with my plan: involved in CLP activities such as NAS, adventure group and speaker groups; socialisation, community access."

Increased Qualify of Life

"I was able to get a job".

"I can do the things that I want to do like staying fit and healthy".

"I'm able to do exercise and have a personal trainer".

"It has provided me with lots of opportunities – I got sports, musical rehearsals, have a support worker to take me to shopping".

"It has given me what I need to help me improve my life – I got a walker, a bar to help me get up, I got an electric recliner".

"With NDIS funding, I can do things that I could not do before such as having a key worker and support worker to provide support around transport, grocery shopping and cooking".

Increased Choice

"NDIS let you choose if you want to self and plan manage, I chose plan managed so I get someone to keep track of my funding."

Interactions with the NDIS

"Having access to my government portal, no problems accessing NDIS portal, get through on the plan with NDIS quickly."

"I got to do a face-to-face meeting."

"I got respect from NDIS staff."

"Carers Queensland – treated me better, respect, asked me what the problems were, kept in touch."

"Get to talk to NDIS staff, very helpful."

"NDIS staff responded quickly."

"NDIS staff at Chermside location are quite nice, they ask easy to understand questions, friendly."

"I get my point across."

What is bad about the NDIS?

How the NDIA treat people

"They are providing service, but they are not practicing according to their mission/live up to their values. Say one thing and don't practice according to their mission and values".

"We didn't get to see anybody – they don't pay too much attention".

"Treated people as a number, I felt like just a number".

"Not consistent in customer service, some staff are not nice".

"Clients don't matter, some are treated better than others".

"Carers Queensland keeps ringing and asking how my plan is, it annoys me".

"I like having face to face meetings with NDIS staff".

"Communication is bad"

"Sometimes I am ignored, or not listened to, to be understood".

NDIS Processes

"Process is too long and unclear, took a while to get back to me."

"Process is too complicated".

"I don't like how they keep changing the contact person for my plan".

"The system doesn't let you tell them that you've given all the information you've given them. Too bureaucratic, no system to tell the system that you've given all the information you have. Left in the dark on who to contact to get the support to work on the goals that are part of your plan, in my first plan."

"System needs to be more consistent".

"Not using common sense in the application of the NDIS rules".

"Underfunded and understaffed – goes back to politicisation".

"When I tried to get on to the NDIS, they kept asking for more information when I had already given them all the information I have and can give them. It is a waste of time getting all the paperwork to reword what you've already given them – waste of time, effort and money".

"Bureaucracy, red tapes".

"Not transparent".

"Power difference is evident".

"No chance to review plans before they go through the system, no chance to be part of the review/decision of the plan".

"I need to be consulted about changes to my plan, which they should do".

"I get to write what I want for the NDIS, and I get my support worker to help me send it to NDIS without having a face-to-face meeting, it's not personalise[d]".

Planning and Funding

"The plan needs to be longer than 2yrs".

"Old plan should be used up first because I still have money on it before using the new plan".

"Services raise prices and funding is the same".

"The funding is restricted. You can only use some funding for some things. If you were able to use every bit of your funding for everything NDIS offers, that would be good".

"Cuts to funding."

Unmet Needs

"NDIS look more on physical disability"

"New SIL application was declined".

"Funding is cut – now, less hours spent by workers".

"Having no support coordinator in your first plan is going to make things very difficult to get things done to support you around your goals".

Services

"Assisted living, were paying exorbitant rent and this needs to be looked at".

What would you change? What ideas do you have to fix the problems?

Unmet Needs

"Need more hours from social workers"

"I get 2hrs/week support from social workers and should get more social worker support hours if I need it".

"I need the sleep apnea machine so I'm hoping I'll get it".

"Support on a weekend is very important"

"Make sure that I have enough funds to cover the things that I need to make sure that I am on top of my budget / on track of my budget".

"In my opinion, there are lots of homeless people, I think it would be better if NDIS can provide housing for them as well".

NDIS Processes

"Having the right procedures/process in place around requesting and receiving information".

"The people on top of the hierarchy get paid more, but do not spend time with clients".

"System needs to be overhauled."

"We need the ability of staff to review plans before they go live to make sure there's no errors or shortfalls".

"Would be easier if there was not lots of paperwork."

"Pay attention to what they are doing" (increase accountability).

NDIS Staff Training

"Staff should have qualifications and knowledge about intellectual disability".

"Hiring of NDIS staff, the process needs to be looked at".

"Better NDIS workers who understand people with intellectual disability".

"Trainings for staff around customer service, communication"

Plans and Funding

"I'm hoping that NDIS will stop cutting funding".

"Some constituents need one-on-one [in group settings] and this should be maintained as some may have a hard time adjusting if there's too many people"

"NDIS need to continue to cover things that I enjoy doing. Building/doing things with my worker is very important".

Be Person-Centered

"Start listening to the clients"

"Respect, trust, need to be person centred"

"Put trust back to people"

"Take the client seriously not a number, person is important."

Other

"Number one – get the politics out of the NDIS,
Number two – having a way to let the system know that you've given all the information that you have so they stop asking for more information that you don't have any more,
Number three - able to review plans before they go live".

"NDIS - should be renamed into something friendly coz I really don't prefer the word Scheme".

View of Parents and Informal Supporters

The following section is a summary of interviews that were conducted by CLA of NDIS participants' parents and other informal supporters. Nine people were interviewed in total. Informed consent was obtained to include their views in this submission, and people have been de-identified.

It is noted that interview respondents represent a small sample of total CLA parents and informal supporters. Their views and experiences may not be representative of the people who were not able to participate in this process due to barriers presented by complex disadvantage and social marginalisation.

What is good about the NDIS? What are things you like about it?

Quality of Life and Rights for People with a Disability

"In theory it is good. People get the funding and live a fulfilling life with safety and respect."

"It gives people quality of life."

"The NDIS is an investment. With the right plan it will lead to more positive results for persons living with a disability, for their families and carers but also for a more inclusive community, country and world."

"The NDIS has decreased disability discrimination; with the NDIS, many persons with disability have better support to access education, intervention and very importantly work to feel empowered."

"NDIS allows the community to discuss and visualise disability in a positive and forward-thinking way, at last!!!"

"The NDIS has improved our quality of life as a family, as many more persons living with disability are now able to be out in the community in general it has increased Australians awareness and acceptance of disability in everyday settings such as shopping centres, libraries, and social settings."

Access to Supports

"As a single parent and carer to 2 sons with significant disability the NDIS has allowed me to return to work and feel empowered again to play a vital role in our community".

"With the NDIS, my son is able to live independently, with necessary support, in his own home."

"NDIS has increased the variety and access to services that were not as readily available before".

"With NDIS funding, my son has a network of support and is happy with it."

"It allows young adults living with disability to improve their independent living skills, social skills and self-confidence".

"Able to afford mobility aids and costs of caring."

"Provides opportunities for care that we otherwise wouldn't get (E.g. mobile physio, can't do it on long term basis due to high cost of care to come to nursing home)".

"NDIS has allowed my profoundly disabled son to access equipment which has improved his quality of everyday life".

"Funding has provided things necessary to live comfortably for me and my daughter. Improved my daughter's life in many ways and helped her to do the things that she would like to be able to continue doing in her life".

Increased Wellbeing

"It gives our family the ability to access vital interventions required for my sons to lead happy and fulfilling lives".

"Helps with therapy, behaviour plans as my daughter is having problems coping with lots of people".

"It allows my son to socialise with peers in a supported way to improve his mental health."

"The NDIS has also improved the quality of services/support workers as it is governed and monitored more now".

"Care services are improving."

Support Coordination

"Having a support coordinator who understands and supports your family. It is a mechanism of monitoring those more vulnerable in our community and to connect them with best match services for their loved ones".

What is bad about the NDIS?

How the NDIA treats people

"At that time my request for funding for my daughter's case, the response was NO. It was not approved! The Home and Living team could not give any reasons for the decline. It was a much longer rejection; I was waiting for quite some time for the decision to come out, but they did not approve my case in the end. There were no explanations provided except for degrading comments about my daughter's conditions. It was so demeaning, humiliating and caused further mental health issues for my daughter and for the rest of the family. The NDIS staff have no empathy and accountability. We felt disempowered. Thanks to Community Living Association (CLA) who helped put the case to tribunal to appeal. The CLA Support Coordinator also helped me get legal support / solicitor. Suddenly, NDIS contacted me to have a meeting and finally approved my daughter's funding to stop my case to go to tribunal. Appeal decisions is a waste of time, money, and effort."

"NDIS needs to be more communicative, when need to ring up NDIS it's the answering machine who pick up the phone".

"Not enough support for families, I have waited over 6 weeks and multiple phone messages and finally contacted my local member just to get a reply from NDIS!! Appeals regarding assistance/access and funding/support and general plan information go unanswered for lengthy periods of time, again posing harm/damage to the person with disability or their families/carers".

"Make planning fair, listen to the person living with disability and loved ones, provide funding of appropriate plans, presently this is not occurring for every person on the NDIS".

"The expert in this process is not the NDIS assessor but the parent/carer, I have studied Autism for 23 years now, 24/7 I have my masters really, so please respect the input/information provided by these persons, don't judge, but listen and give control to the person living with the disability or their families to deliver a plan that will provide them with optimal outcome with a happy and fulfilling life".

"NDIS staff are very unprofessional, no empathy and lack of accountability!"

"The level of understanding of staff disability. I am curious about their qualifications."

NDIS Processes

"NDIS operate like a secret organisation."

"Planning process is very confronting, supposed to be done by participants or nominee and you really need someone to guide you through the process".

"Hard part, review plan it takes forever. We had a review done and were coming to the end of the funding. The new plan took a while."

"Waiting times for the decision of new plan is too long, when funding is rolled over, parents are not consulted about it or not part of the decision. Obviously, they're trying to save money so they roll them over but they aren't allowing participants to actually speak up and explain their current circumstances as well as change in circumstances".

"Persons identified with significant lifelong disability that will not change but only increase in need should be placed on a lifelong plan, with the availability to increase funding when the need occurs and should not be submitted to plan review after plan review. It is heartbreaking, and also very stressful. This scheme could be done so much better, if you put people in place with actual knowledge around disability care and its immense needs".

Plans and Funding

"The hours are not enough to compensate the work that needs to be done".

"Changes in the cost of living need to be factored into NDIS plans, prices set by the NDIS do not cover the costs associated with the delivering services under the scheme leaving families out of pocket again!!".

"Keep reducing funding. NDIS gave money initially but took it back. We came to review; NDIS told us what they think and gave funding without considering the participant's opinion".

"Many plans are not adequate to meet the person's needs, and many of these do not have advocacy for them. For many vulnerable persons and families this places them at enormous risk of injury, harm, multiple hospitalisations and even relinquishment of loved ones".

"It doesn't provide security – NDIS plans are daunting; we fear funding won't be continued".

"Very bureaucratic, plans are confusing".

"In general, is lack of communication and maybe there are not enough workers in NDIS to have time to really sit down with parents and look at the case and what it is all about".

"The NDIS is very focused on the diagnosis not the individual functionality of person living with the disability, especially for persons with significant disability".

"The cost associated around the evidence requested from health professionals should be reimbursed to families. Persons with significant disability where very little change will occur in their functionality are again and again requested to provide heartbreaking reports/assessments to justify their NDIS plans, with often very little understanding of the report by the assessor, this is a waste of time, effort and money. The recommendations of the long term experts (me) in my case shouldn't be second guessed or discarded by an unfamiliar/inexperienced NDIS staff member!!".

"My son is severely intellectually impaired plus has schizophrenia, and accordingly, needs 24/7 support. This will never change. However, we are required to substantiate this fundamental fact every review. Fundamental, unchanging needs should not be required to be substantiated more than once. It is unnecessarily costly and time consuming to have an allied health professional prepare a report on a situation which has not and will not change. This also is very stressful for the constituents and their families".

Inequities

"In my opinion, there is a socio-economic bias in the NDIS, if you're someone like me has an educated background who is used to asking what they (people with disability) need/want or can present a good argument, I believe / feel that we're more successful. E.g., if a person with a disability doesn't have someone who can back up / advocate for them, they won't get much funding".

"Another problem is the need is greater than the availability of services, and you cannot pay for a service before it is provided therefore many families miss out on services as it is the first to pay that get into the workshops/therapies, this needs to be assessed".

"I believe in the assessment, but the cost is very high and that takes away the budget e.g. physio".

Safeguarding

"There should be regular emotional/welfare checks on primary carers with loved ones with significant disabilities. This did not occur during COVID when no support workers were able to access the home and it was me 24/7 with my 2 sons. I only received 1 phone call for check in".

"Monitor vulnerability of participants and provide advocacy around plan funding and appropriate implementation of the plan funding".

"NDIS accredited service providers are more expensive".

What would you change? What ideas do you have to fix the problems?

Increase Accountability

"Communication has to improve, plan updates/changes/reviews should be communicated to all parties, participant/carer/parent/support coordination. Presently this does not occur and does not occur in appropriate time frames".

"Home and living team – they should be more accountable, contactable, should organise a meeting and look/read the paper that we submitted to them".

Simplify Processes

"Processes should be simplified, personalized, and NDIS [participants] and their family and supporters should have the opportunity to have a voice and provide more information before the plan is rolled over".

NDIA Staff Training

"STAFF TRAINING!!!! Employ persons living with a disability or parents/carers. A scheme run for people with disability should be a scheme run by people living with or loving someone with a disability!!".

"NDIS staff can give better explanations on how the NDIS works if given the right training".

Focus on Empowerment

"More empowerments should be given to people with disabilities around their plan development, this does not occur as it runs the risk their funding will be reduced as their input is not respected enough by the NDIS team".

"Constituents and supporters should be part of the process – NDIS should not operate like a secret agency".

"Provide/give better understanding on how NDIS work".
"You need to give a voice to the experienced participants/families/carers who have a wealth of knowledge on what works and what needs to be changed to the NDIS scheme so to positively transform the lives of the very loved half million Australians living with disability including my 2 beautiful sons L & M!!".

"Link NDIS and Centrelink with more respect to persons with significant disability, provide an NDIS support person for DSP issues at Centrelink. Disability does not go away; to be judged as we are by NDIS and Centrelink presently is disgraceful".

Plan Reviews

"Make planning fair, listen to the person living with disability and loved ones, provide funding of appropriate plans, presently this is not occurring for every person on the NDIS".

"I suggest that fundamental, unchanging needs should be established in the initial plan and thereafter only additional issues should be the subject of the plan review and discussion".

"Where possible, NDIS client plans should be reviewed by the same staff person for consistency. Where that is not possible, there should be interview notes sufficient for the next reviewer to be informed as to the client's fundamental issues and needs, interests and concerns".

"Inconsistency in plans for participants with similar needs should be assessed on a compliance scale to capture failures in the system to maintain standards of care".

"I suggest there should be a commitment by the NDIS to process and approve plan reviews within reasonable time frame. No more than 30 days, I would consider to be reasonable".

"Time frames around plans being approved or plan reviews to be addressed needs to have a set time limit set to it so targets have to be met and data collated for service delivery targets".

"People need support developing a plan from case managers or support / plan managers with a knowledge base. They should go to NDIS with a plan to be approved rather than waiting to find out how much funding they are going to get and develop a plan around the funding that has been granted".

"There should be planner with only limited power - to recommend, listen and talk."

"Many people with disability are not "gonna get better", therefore talking about an outcome-based funding, doesn't provide them with security and confidence in the NDIS".

"Security – e.g. if offered 2hrs physio per week, we shouldn't go to plan meeting and be concerned it would not be approved / included in the next plan".

Safeguarding

"Should be regular emotional/welfare checks on primary carers with loved ones with significant disabilities this does not occur during COVID when no support workers were able to access the home and it was me 24/7 with my 2 sons I only received 1 phone call for check in".

"There should be emergency 24/7 services available to families, if because of injury or risk emergency care can be implemented immediately not in days or weeks".

Sustainability

"The NDIS has to be presented to the greater community in a positive fashion. I am so sick of hearing how much it costs taxpayers and not hearing how it can significantly changes the quality of life of a person with a disability. This has a negative impact on the community and their views of disability, and needs to stop. The constant focus on cost cutting a system designed to help the vulnerable persons with more challenges living with a disability is shameful and as a country it needs the model reshaped by the right people and that needs to occur now!!".

Services

"The NDIS price guide rates should parallel the SCHADS award rates".

"Lower the NDIS fees, cut assessment fees from the companies who charge it".