



Issues facing participants with complex support needs in the NDIS

Background Paper – NDIS Review

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This paper was prepared by Katharine Annear, Flinders University, to support Inclusion Australia's engagement with people living with intellectual disability, their families and allies, and other stakeholders as part of consultations to inform the NDIS Review.

Introduction

This paper is designed to give an overview of issues for participants with complex needs in the National Disability Insurance Scheme (NDIS). The paper discusses four main themes – the definition of complex needs, choice and control, restrictive practices, and participant voice. There are case studies that highlight real life experiences and finally suggestions for improvement to be discussed for the NDIS Review.

Complex Needs

Complex needs is a term that has many different understandings in the disability community. A person may have physical and health needs requiring a high level of complex personal care, they may have multiple systems involvement requiring a high level of complex coordination, they may have multiple diagnoses that led to a high level of complexity at an individual level.

One of the standout issues for participants their supporters and nominees is the differing definitions of complex needs. The NDIS complex needs pathway provides support to people who have multiple systems involvement. People on this pathway may have housing, justice, and health needs or a similar mix of multiple system involvement that means there is complexity needing coordination.

Traditionally in developmental disability complex needs has meant those with multiple impairments i.e., having intellectual disability, autism and being nonspeaking, or having intellectual disability, psychosocial disability, and behaviours of concern. **Complex needs** in developmental disability has been a term associated with complexity at an individual level rather than at a systems level.

Many parents or participant nominees cannot understand why the complex needs pathway is not available to them when the participant has been diagnosed as having developmentally complex needs for their lifetime.

This is an area where parents of people with developmental and intellectual disability feel like the scheme is failing in comparison to those participants who have high physical needs (Bigby, 2021).

Parents and nominees also report a lack of knowledge about the complex needs pathway and how to access it.

Unfortunately, those with developmentally complex needs must fall into a crisis that requires multiple systems involvement before being thought of as complex needs by the NDIA.

Parents and nominees do report anecdotally that once they have access to the complex needs pathway there is a great deal of attention given the participant and their needs and a greater deal of communication and coordination from the NDIA regarding planning and plan implementation.

This is in comparison to many unsupported parents who feel that they have taken on a second job coordinating NDIS supports:

“It feels like I have a new full-time job implementing the NDIS and negotiating contracts, searching for providers, trying to get them to come to our community.”

(Lloyd et.al., 2020)

Case Study

Jack and Marie are parents to 22-year-old Matthew. Matthew has autism, intellectual disability, anxiety and is unable to communicate without a communication partner. Matthew also has very high behavioural support needs. Jack and Marie have always been told that their son has complex needs. However, they have been told by the NDIA that they are not eligible for the complex needs pathway because they do not have multiple systems involvement. Matthew still lives in the family home and Jack and Marie are aged in their 60s. Jack and Marie self-manage their sons plan and spend hours a week dealing with budgets, staffing, and reporting on top of being involved in the 24/7 care that Matthew needs. Jack and Marie are very concerned that their situation will have to deteriorate to a point where they have multiple systems involved to get a higher level of support from the NDIA.

Suggestions for Improvement

That the NDIA work with participants and nominees to define complex needs so that there is a community wide understanding of what complex needs means.

That complex needs support be made available to people with complexity experienced at an individual level.

That complex needs pathways are clearly communicated to participants and participant nominees so that access can be made easier.

That there be an investment in skilled complex needs planners in specialised teams with knowledge of different types of complexity that participants experience.

That NDIA planners and partners in the get decision making support to understand when refer people with complex needs to the appropriate pathway.

Choice and Control

One of the central ideas in the NDIS is choice and control. According to several researchers (Bigby, 2020; Horsel, 2023) having choice and control relies on participants having the skills to use that choice and control. As pointed out by Christine Bigby (2020):

“They (the NDIA) privilege self-defined needs, and assume participants have capabilities to lodge claims, articulate needs, make decisions, identify and exercise control over service delivery and access social capital.”

NDIS Legislation assumes that participants will direct their planning process and supports (Bigby, 2020) without allowing for the individualisation needed for people with intellectual disability, complex needs, and/or those who have never had a chance to learn these new skills (Bigby, 2020; Horsel, 2023).

Lloyd and others (2020) found in their study that people with intellectual disability either did not participate in or were not present at planning meetings with the NDIA. Self-report from parents of people with complex needs tells us that participants are rarely present at planning meetings.

To use the choice and control promised by the NDIS parents, carers and nominees must be an ever present 'case manager' seeking adequate funds and opportunities. This not only costs family members' time but can also deny people with disability a role in making decisions about their own lives (Bigby, 2020).

When it comes to the availability of services and choice and control for people with complex needs, the market is failing in many ways.

Parents and nominees report that providers 'pick and choose' clients and will often choose to support clients with less complex needs leaving few or no opportunities for accommodation and community access supports. This is a much greater issue in rural and regional areas where there are so few, if any providers, or a single provider monopoly (Considine, 2022).

For people with complex needs, models of service provision have not changed because of the NDIS. One parent describes having to choose between 'day options' services for her daughter:

"We visited a few services and our daughter refused to stay because the buildings were old and smelt bad, one place said she was too challenging when I suspect she was just bored and didn't like being kept in a smelly building. Where she attends now is a new building, they provide the right level of staffing, but the staff don't have the skills to engage her. They also charge in blocks of 6 hours even though my daughter only attends for 3. We don't want her to be socially isolated so this the only option."

Lloyd and others (2020) found that new opportunities for people with intellectual disability provided by the NDIS were either solo (supported by a worker) or segregated. In the case of people with complex needs individual or solo community access often occurs with 2:1 staffing or not at all due to lack of funded supports. As demonstrated by the quote above the same types of group programs are running from the same facilities as 10 or perhaps 20 years ago. Any attempt by the NDIA to guide innovation and reform in these areas seems to have failed.

Many participants with complex needs still live in the institutional settings that they lived in before the NDIS. Those moving into new accommodation move into settings that are like small institutions with set routines that suit staff and a high turnover of staff with entry level qualifications. There have been several highly publicised cases where parents have rescued their adult offspring from poorly run group homes or other accommodation facilities, and sadly there have been recent deaths in accommodation settings highlighted by the Disability Royal Commission.

Where the right housing and staffing ratios are provided many parents still feel like they provide a backup system, and report feeling like they are 'on call 24/7' in case something goes wrong at the house.

Parents often have to provide decision making support for staff because it is not available from employers. In one NSW study of the NDIS workforce, 59 % of workers reflecting on supervision and support said they had to make decisions about client safety, care and support on their own (Cortis & van Toorn, 2020). In the same study unsupported decision making was also prevalent among less

qualified workers: over half of those with less than a Certificate IV level qualification said they had to make important decisions on their own.

Here the market is clearly failing to provide adequate choice and control as there are so few options and many of the existing options are of poor quality.

As Considine (2022) observed, there has been no intentional process of investing in new service development alongside the current service mix. Considine also highlights that the *“very significant costs of developing these services almost certainly means that there will never be the kind of ‘spare capacity’ necessary to furnish participants with an array of choice.”* He says that the NDIS has failed to guide the development of new services and instead has believed that consumer choice would somehow sort out the bad and encourage the good. In the area of complex needs specifically there is too much risk in leaving a poor service to find a better one. One of the biggest frustrations with this situation is that the NDIS continues to fund poor services and does not take an active role in requiring service improvement.

Case Study

Myra is single parent to Ashley who is 24 and has an intellectual disability, autism, is non-speaking and has very complex behavioural support needs. Ashley has never attended a planning meeting with Myra. Ashley lives in a single occupancy dwelling with supported independent living funding. Ashley is supported 24/7 with a 2 to one staffing ratio. Ashley rarely accesses the community because the staff have not developed the necessary skills to prepare him to go out and to keep him and others safe in the community. Myra is deeply concerned that Ashley is very isolated and that the only people that he sees are paid staff. Myra feels that they have no choice and control within the NDIS and that Ashley is living in a situation that is more like a prison than supported independent living. Myra feels that the risk of abuse is very high because staff are poorly equipped to support Ashley.

Suggestions for Improvement

That the NDIA recognise that people with developmental and intellectual disability with complex needs have unique barriers to choice and control and that supports should be provided to assist people to have choice and control need to be unique and individualised.

That the NDIA supports parents, carers and nominees in their role as decision makers and coordinators of care for people with complex needs. Including supports to involve people with complex needs in decisions about their lives.

That the NDIA directly invest in the creation of services that meet the needs of people with complex needs, addressing ‘thin markets’ and gaps in rural and regional areas and that these services are appropriately funded to provide high intensity supports delivered by qualified and well supported staff.

That the NDIA take an active role in ensuring improvement in the quality of services, including regularly checking on services that provide high intensity supports.

That new and existing supported decision-making programs for participants understand the unique barriers to choice and control that people with complex needs face.

Restrictive Practices

Regulating restrictive practices is the role of the NDIS Quality and Safeguards Commission. The Commission talks about five types of regulated restrictive practices:

- chemical restraint
- environmental restraint
- mechanical restraint
- physical restraint
- seclusion

There are rules about how and when restrictive practices can be used and each time a restrictive practice is used this must be reported to the Commission. Australian States and Territories also have their own rules about restrictive practices and each State or Territory must give permission for a restrictive practice to be used. Restrictive practices are written into a plan called a Positive Behaviour Support Plan which can only be written up by a registered Positive Behaviour Support Practitioner.

Many people find this information about restrictive practices and behaviour support hard to understand. Amongst those who find it most difficult are participants, family members and support workers. Arguably the people most affected by the use of restrictive practices.

The use of very technical positive behaviour support plans to talk about and record the use of restrictive practices has made the whole process inaccessible to the people they affect the most.

This lack of accessibility sometimes means that families and support workers are too nervous to reduce restrictive practices. They may not have enough information about how the strategies will work or they may be used to using restrictive practices believing that that is the only way to be safe.

People with disability have the same human rights as everyone and one idea behind regulating restrictive practices was to make sure that people with disability could be free from harm. However, government and organisational policies on behaviour support have instead become 'permission' to use restrictive practices (Hayward et.al. 2023). This is because many policies talk about how and when to use restrictive practices rather than focusing on human rights and reducing restrictive practices.

This means the use of restrictive practices is becoming normalised (McAlpine in Richards and Lavelle, ABC News, 2023) with a 5-fold increase in the reporting of unregulated restrictive practices (Richards and Lavelle, ABC News, 2023).

Hayward and others (2023) say that when permission is given to use restrictive practices for 'safety' reasons this covers up the use of power. In this case it is the use of power over people with disability.

The idea behind Positive Behaviour Support (PBS) is a commitment to fixing environments not fixing people (Hayward et. al, 2023) Hayward says that PBS plans should lead to a capable environment that upholds the rights of people with disability. He also says that PBS plans do not necessarily lead to a reduction in challenging behaviour.

Unfortunately, though, under the NDIS 'a PBS plan' is not a human rights instrument it is a permission slip for restrictive practices.

When taking a focus on upholding the rights of people with disability PBS is not the only model or approach to understanding and/or improving behaviour in people with disability. There are socio-ecological approaches (Sutherland et al. 2022), psychosocial models (Greene & Winkler, 2019; Murrihy, 2023), and relational approaches (James et. al. 2021). Features of these approaches include focusing on societal, social, environmental, and relational factors and changing the perspectives and attitudes of people who support and engage with people with disability. Also key to these approaches is not seeing the individual as the site of the problem and looking for ways to engage people with disability in the solutions.

Case Study

Paul is 35 years old, has intellectual disability and lives in supported accommodation with 24 hour active staffing. When Paul had a behaviour assessment they also reviewed his medication. A new psychiatrist found that Paul had been prescribed medication to keep him calm. This medication was designed to treat schizophrenia which Paul doesn't have. The psychiatrist also found that Paul was being given three times the normal adult dose of the medication as well as extra doses when needed (PRN). This is an example of chemical restraint. The psychiatrist recommended that Paul's medication be reduced safely but as soon as possible, and that the PRN be stopped straight away. All of this was recorded in a positive behaviour support plan along with strategies to support Paul. Paul's support staff were given a 3-hour training on the behaviour support plan from a forensic psychologist. Staff then made a complaint to their supervisor about reducing the medication and removing the PRN saying that it wasn't safe to work with Paul if he was on less medication and they couldn't give PRN.

Suggestions for Improvement

That Legislation, Rules and Guidelines be amended to focus on:

- Prioritising the human rights of people with disability and the reduction and elimination of restrictive practices
- A harmonised national authorisation and monitoring scheme
- A common law approach to unauthorised use of restrictive practices meaning unauthorised = unlawful
- A requirement for each provider to have a registered reduction and elimination of restrictive practices plan.

That informed written consent be given by the participant or guardian for the use of restrictive practices and appropriate decision-making support be given to those consenting.

That the authorisation and monitoring of the use of restrictive practices be decoupled from behaviour supports.

That any behaviour support framework that is used must be focused on human rights, quality of life, be person centred and focus on capable environments.

That practitioners working in behaviour support be degree qualified in disability practice and one or more methodologies of behaviour support and have the technical skills to implement organisational plans to reduce and eliminate restrictive practices.

That there be communication standards for behaviour support planning and reduction and elimination of restrictive practices plans to make sure that they are accessible to participants, families, and support staff.

Participant Voice

This paper is lacking the voices of people with complex needs. Much of what we know via research or report comes from parents, carers, advocates, and service providers. We know very little about people with complex needs who are hard to reach – people without family or advocates, those living in institutions, First Nations and Migrant people, people who are homeless and people in forensic justice settings. We know that researchers, agencies, and service providers often lack the time, skills, and resources to engage with people with complex needs. There are new research projects that focus on hearing the voice of people with disability and complex needs. To really focus on the needs of people with complex needs we need to find new ways of engaging and listening to people. We need to acknowledge that this takes skill and most importantly it takes time. When we decide to make changes to a big system like the NDIS we need to allow the time it takes to listen before we make changes.

Resources for including people with complex needs in research:

- Dee-Price, B.-J. M. (2020). Social researchers and participants with intellectual disabilities and complex communication (access) needs. Whose capacity? Whose competence? *Research and Practice in Intellectual and Developmental Disabilities*, 7(2), 132–143. <https://doi.org/10.1080/23297018.2020.1788418>
- Fudge Schormans, A., Wilton, R., & Marquis, N. (2019). Building collaboration in the co-production of knowledge with people with intellectual disabilities about their everyday use of city space. *Area (London 1969)*, 51(3), 415–422. <https://doi.org/10.1111/area.12492>
- The Complex Needs Research and Development (COMRAD) Project <https://comradhub.com/>

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Richards, S. & Lavelle, L. (2023) The number of reports of unauthorised restrictive practices to the NDIS is up five-fold in three years, to 1.4 million. ABC News Report.

<https://www.abc.net.au/news/2023-05-19/qld-ndis-rise-in-instances-of-unauthorised-restrictive-practices/102356712>

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