National Eating Disorders Collaboration

Evidence Experience Expertise

Summary paper: NDIS engagement for people with eating disorders

August, 2023

Contents

List of acronyms

ADHD – Attention Deficit Hyperactivity Disorder

APTOS – Applied Principles and Tables of Support

ARFID – Avoidant/Restrictive Food Intake Disorder

ASD – Autism Spectrum Disorder[1]

BED – Binge Eating Disorder

DoHAC – Australian Government Department of Health and Aged Care

DSS – Australian Government Department of Social Services

ED – Eating Disorder

EDV – Eating Disorders Victoria

NDIA – National Disability Insurance Agency

NDIS – National Disability Insurance Scheme

NEDC – National Eating Disorders Collaboration

OT – Occupational Therapist

SE-AN – Severe and Enduring Anorexia Nervosa

SE-ED – Severe and Enduring Eating Disorder

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[1] This terminology is occasionally used in direct quotes. NEDC typically uses the terms Autism or Autistic in line with community preferences. Further reading: https://nedc.com.au/assets/NEDC-Publications/Eating-Disorders-and-Neurodivergence-A-Stepped-Care-Approach.pdf

Introduction and context

The National Disability Insurance Scheme (NDIS) has been operational in Australia for ten years. In that time, the Scheme has rolled out from initial trial sites to now cover the entire country. It supports over 500,000 people with disabilities through individual funding packages aimed at improving quality of life through increased participation in economic, social, civic and community life (National Disability Insurance Agency, 2022a).

Eligibility for NDIS access is met according to three key criteria: age, residency and disability. If a person under 65 years of age resides in Australia and meets the disability requirements (outlined on page 4), they may access the NDIS and, through it, funded supports according to an individually tailored plan. A wide range of diagnostic categories may be covered by the disability requirements, as the policy intent is for the NDIS to meet people's functional needs (National Disability Insurance Agency, 2021). There are, however, some diagnostic groups where eligibility is either less clear, or at least less well understood by those who assess requests for access. One such group is eating disorders.

Eating disorders are complex and serious mental health conditions, often with physical and functional consequences (Hay et al., 2017). While not all people with eating disorders will have a lifelong condition, and indeed recovery is possible for many, there remains a cohort of people whose eating disorder is longstanding and likely to persist across the remainder of their life (Kotilahti et al, 2020). Eating disorders have among the highest mortality rates of all mental health conditions; this is particularly the case for, but not limited to, anorexia nervosa (van Hoeken & Hoek, 2020). A recent rapid review of outcomes for people with eating disorders found that less than half of people in long-term follow up studies had achieved recovery (Miskovic-Wheatley et al, 2023). Recovery rates for anorexia nervosa ranged from 18-60%, for bulimia nervosa from 35-59%, and for binge eating disorder from 37-77%. Long term recovery rates for other eating disorders had limited data available.

It has been suggested that some people within this cohort ought to be considered eligible for the NDIS, and publicly available data from the NDIS shows that a small number of people with eating disorders do have NDIS access (National Disability Insurance Agency, 2023). Nevertheless, substantial anecdotal feedback from people with lived experience and the people who support them suggest that requests for NDIS access are frequently rejected on the basis that eating disorders are seen as ineligible.

An additional cohort of people with eating disorders who may be eligible for the NDIS are those who have an eating disorder and a primary disability of some other kind, such as Autism, Attention Deficit Hyperactivity Disorder (ADHD), Depression, Anxiety and more. However, the degree to which this group of service users are able to access and receive the care they need through the NDIS scheme remains unclear.

This paper seeks to address these gaps by examining the accessibility, engagement with, and suitability of the NDIS for two groups with living experience of eating disorders:

- People with a longstanding eating disorder as primary diagnosis, and;
- People with an eating disorder and a co-occurring condition.

Key inputs

This paper has been informed by a desktop review of relevant legislation and policy documents, as well as publicly available data on NDIS participants. These sources have been further supplemented via direct contact with representatives within the National Disability Insurance Agency (NDIA) and the Australian Government Department of Social Services (DSS).

In addition, a public survey was designed to receive direct input both from actual and prospective NDIS participants with eating disorders, their carers and the professionals who support them.

Individual case studies have also been sought and are presented in each person’s own words. NEDC thanks all of these people for contributing their lived experience expertise.

This work has been guided by an oversight group comprising lived experience and clinical expertise, all with direct experience of engaging with the NDIS and supporting others who have or are seeking access to the Scheme. NEDC thanks them for their support in this work.

This work was funded by the Australian Government Department of Health and Aged Care (DoHAC).

Summary of findings

Policy overview

NDIS eligibility criteria

NDIS eligibility criteria are set out in the National Disability Insurance Scheme Act 2013 (the Act). Assuming a person meets age and residency requirements, the disability requirements are, pursuant to Section 24:

(1) A person meets the disability requirements if:

(a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or the person has one or more impairments to which a psychosocial disability is attributable; and

(b) the impairment or impairments are, or are likely to be, permanent; and

(c) the impairment or impairments result in substantially reduced functional capacity to undertake one or more of the following activities:

(i) communication;

(ii) social interaction;

(iii) learning;

(iv) mobility;

(v) self-care;

(vi) self-management; and

(d) the impairment or impairments affect the person's capacity for social or economic participation; and

(e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.

(2) For the purposes of subsection (1), an impairment or impairments that vary in intensity may be permanent, and the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime, despite the variation.

(3) For the purposes of subsection (1), an impairment or impairments that are episodic or fluctuating may be taken to be permanent, and the person may be taken to be likely to require support under the National Disability Insurance Scheme for the person's lifetime, despite the episodic or fluctuating nature of the impairments.

(4) Subsection (3) does not limit subsection (2).

There are no diagnosis-specific inclusions or exclusions set out in the Act. It is reasonable that an eating disorder (as a psychiatric condition) could be considered a psychosocial disability, and may have additional physical or cognitive dimensions (e.g. complications of prolonged malnutrition). It is also reasonable to anticipate that some people's eating disorders may be likely to be permanent, as discussed above, and may impact on areas of functioning including any of those set out in 1c.

Separately to the Act, the NDIA publishes a series of four 'access lists' (National Disability Insurance Agency, 2022b-e). These lists set out a number of diagnostic groups where people with these conditions are likely to meet the disability requirements for NDIS access. While the initial policy intent of these lists was to expedite transition to the NDIS for people who had previously been provided services under state or territory disability funding, the lists appear to have retained a function although the NDIS is now at full Scheme, and continue to be used to expedite access requests for people with listed conditions. Anecdotal evidence suggests that conditions that are not included in the access lists are commonly viewed as 'not eligible' for the NDIS. Advice regarding this was sought from DSS and NDIA personnel – in each case the advice was that the access lists do not override the eligibility criteria set out in the Act. Neither was able to offer a view as to how the access lists are currently used in practice.

In respect of service provision to those people who have been granted NDIS access, the National Health Reform Agreement 2020-2025 (Commonwealth of Australia, 2020) endorses the continued use of the 'Applied Principles and Tables of Support' (APTOS) first agreed by the Council of Australian Governments in 2015 (Commonwealth of Australia, 2015). The APTOS sets out the responsibilities for the NDIS and for adjacent sectors, including health and mental health, when providing support for a person or their family. According to the APTOS, a person with a mental health condition (psychosocial disability) may receive support from both the NDIS and the health system on the following bases:

1. The health system will be responsible for:
   a. Treatment of mental illness, including acute inpatient, ambulatory, rehabilitation/recovery and early intervention, including clinical support for child and adolescent developmental needs;
   b. residential care where the primary purpose is for time limited follow-up linked to treatment or diversion from acute hospital treatment; and
   c. the operation of mental health facilities.
2. Where a person has a co-morbidity with a psychiatric condition:
   a. The health or mental health system will be responsible for supports relating to a co-morbidity with a psychiatric condition where such supports, in their own right, are the responsibility of that system (e.g. treatment for a drug or alcohol issue).
   b. The NDIS will be responsible for additional ongoing functional supports associated with the co-morbidity to the extent that the co-morbidity impacts on the participant's overall functional capacity. This applies equally where the impairment is attributable to a psychiatric condition and/or is the co-morbidity to another impairment.

3. The NDIS will be responsible for ongoing psychosocial recovery supports that focus on a person's functional ability, including those that enable people with mental illness or a psychiatric condition to undertake activities of daily living and participate in the community and in social and economic life. This may also include provision of family and carer supports to support them in their carer role, and family therapy, as they may facilitate the person's ability to participate in the community and in social and economic life.

4. The NDIS and the mental health system will work closely together at the local level to plan and coordinate streamlined care for individuals requiring both mental health and disability services and supports.

The APTOS also specifies the types of supports the NDIS may provide to a person with a mental health condition (psychosocial disability), including:

- support for day to day living,
- allied health to manage or reduce the impact of the person's impairment on their functional capacity,

- support to access and maintain community participation (including education and workforce participation),
- independent living support,
- social participation support, and
- coordination of supports across both the NDIS, mental health and other relevant systems.

It appears, therefore, that a person whose eating disorder is likely to be lifelong, as well as people with other disabilities who also have an eating disorder, ought to be considered for NDIS access and, if granted, ought to be able to access a range of supports to assist in managing the functional impacts of their eating disorder, alongside any other disability support needs that they may have.

NDIS participant data

According to quarterly reporting data, made publicly available by the NDIA (2023), as at 31 December 2022, there were 573,342 active participants of the NDIS. Of these:

- 127,559 NDIS participants had a psychosocial disability, of which 59,512 (47%) people had a psychosocial disability as their primary diagnosis;
    - 34,580 had schizophrenia, 29,776 (86%) as their primary diagnosis
    - 26,842 had other anxiety disorders, 1,819 (7%) as their primary diagnosis
    - 14,797 had major depressive illness, 5,137 (35%) as their primary diagnosis
    - 9,826 had bipolar disorder, 5,756 (59%) as their primary diagnosis
    - 5,789 had posttraumatic stress disorder, 2,566 (44%) as their primary diagnosis
    - 5,010 had borderline personality disorder, 2,366 (47%) as their primary diagnosis
    - 3,239 had schizoaffective disorder, 2,841 (88%) as their primary diagnosis
    - 2,774 had obsessive compulsive disorder, 295 (11%) as their primary diagnosis
    - 548 had other substance dependency, <11 (<2%) as their primary diagnosis
    - 466 had alcohol dependency, 17 (4%) as their primary diagnosis
    - 220 had Tourette syndrome, 28 (13%) as their primary diagnosis
    - **90 had anorexia, 20 (22%) as their primary diagnosis**
    - 23,378 had other psychosocial disability, 8,881 (38%) as their primary diagnosis.

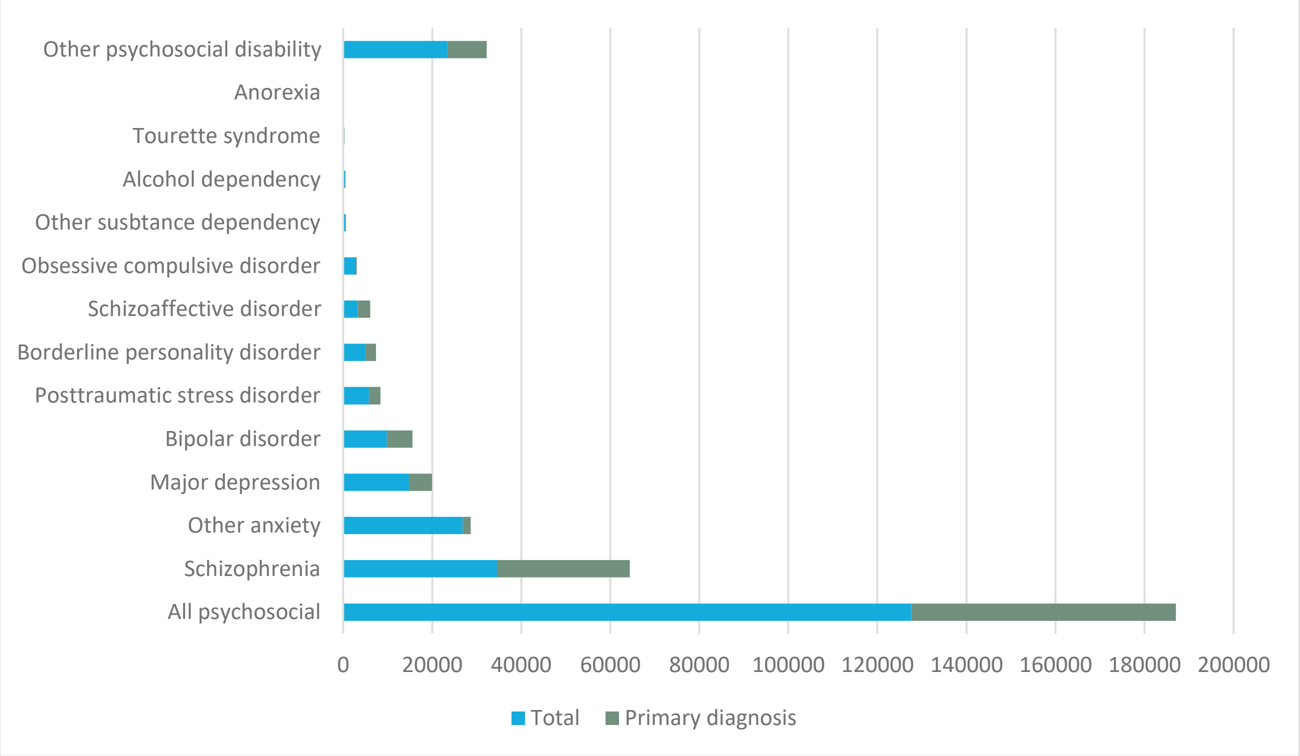

Table 1: NDIS Participants with Psychosocial Disability, as at 31 December 2022

Of the 20 people with a primary diagnosis of anorexia, it was not possible to determine whether anorexia was their sole diagnosis, or whether they also had other conditions.

There was no data specifically relating to any eating disorder diagnoses other than anorexia nervosa. It was not possible to determine whether 'other psychosocial disability' included any specific eating disorder diagnoses.

In addition to the above data regarding psychosocial disability, the following numbers of NDIS participants had diagnoses known to be correlated with increased risk for eating for an eating disorder:

- 215,191 were Autistic[2], 199,367 as their primary diagnosis
- 4,437 were ADHD[3], of which 179 as their primary diagnosis.
- 3,933 had diabetes mellitus, of which 56 people had diabetes mellitus;
- 1,111 were described as having obesity[4], of which 16 people had this as their primary diagnosis;

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[2] Person first language has been used in line with community preferences. Further reading: https://nedc.com.au/assets/NEDC-Publications/Eating-Disorders-and-Neurodivergence-A-Stepped-Care-Approach.pdf

[3] As above.

[4] This terminology is used in this report to reflect the terminology used by the NDIA, however it does not reflect the terminology habitually used by NEDC. NEDC acknowledges the lived experience expertise which has highlighted the harms of using medicalized and pathologizing language to describe bodies of diverse sizes and shapes. Further reading: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5051141/

Survey findings

NEDC ran a public survey to elicit qualitative data about NDIS engagement for people with eating disorders, from 14 – 28 June 2023, promoted via its social media platforms and by some interagency partners.

Seventeen (17) people completed the survey, of which:

- Six (6) had a severe and enduring, or longstanding, eating disorder;
- Seven (7) had an eating disorder in addition to a(nother) disability;
- One (1) was a carer of a person with an eating disorder;
- One (1) was a carer of a person with an eating disorder and a(nother) disability;
- Six (6) were health professionals;
- One (1) identified as a parent of someone with significant feeding challenges and a(nother) disability, but stated that they were unsure whether these feeding challenges constituted a formal eating disorder;
- One (1) identified as a disability and mental health advocate.

The above breakdown of respondents by experience type totals greater than the overall number of participants for the survey as several participants nominated more than one experience type.

People without NDIS access

Several survey respondents said they had been declined access to the NDIS (some multiple times) due to a perception that eating disorders are not covered by the NDIS and are seen as a health system responsibility. This seems to imply that these people had applied for NDIS access as they felt they ought to be eligible, but that someone else involved in the process had the view that they were not. It was not clear from survey data as to whether this may have been a Local Area Coordinator, NDIS Planner or a person in another relevant role.

> "Eating disorders are not covered by NDIS as they are seen to be temporary and not a disability."

People with longstanding eating disorders without NDIS access identified key issues regarding non-recognition of eating disorders and their functional impacts. Respondents in this group expressed frustration at being rejected by the NDIS and described a perceived lack of acknowledgment of the functional impacts and long-term effects of severe eating disorders. The respondents argued that severe eating disorders have significant functional impacts on their day-to-day lives, making it challenging to navigate daily activities and participate in society, arguing that the NDIS's categorization of longstanding eating disorders as temporary and not qualifying as disabilities restricts access to necessary supports and resources. They asserted that the NDIS should recognize the functional limitations caused by eating disorders as a valid reason for support. They also suggested that better awareness and dissemination of information regarding eligibility criteria and available

> "I feel like eating disorders are just deeply underestimated and hard to diagnose as something serious. Especially if you are average or overweight in size like I am."

supports would be beneficial. The overall tone of the data from these respondents reflects frustration and discontent with the current situation regarding eating disorders and the NDIS.

People with NDIS access

All respondents who did have NDIS access (N=5) had both an eating disorder (in some cases longstanding) and another disability. That is, there were no responses from people who had attained NDIS access with only a longstanding eating disorder, though as noted in the previous section there is only a small cohort of people nationally who have NDIS access with primary diagnosis of anorexia.

Among those with NDIS access, there were concerns regarding the extent to which their eating disorder was able to be supported by the Scheme. Respondents in this group expressed frustration with the planning process, finding it vague and lacking clear guidance on which supports can be used specifically for addressing eating disorders. Some also expressed concerns about raising their condition within the NDIS, fearing that it may be dismissed as a mental health issue rather than being recognized as a significant aspect of their disability. They argued that their eating disorders have a direct impact on their functioning and are related to their other physical and psychosocial disabilities.

> “I have not asked for support around my eating disorder as I am concerned that if I raise my eating disorder it will be dismissed under mental health.”

One respondent stated that while they receive dietetic support for their gastrostomy tube feeding as part of their NDIS plan, they require more intensive dietetic support specifically for their eating disorder. However, they find it challenging to obtain this support as it is not considered "reasonable and necessary" by the people involved in developing their Plan.

Respondents highlighted the separation of the NDIS and healthcare, particularly in relation to eating disorders, as a problem. One respondent argued that many individuals with disabilities have complex health needs influenced by their disability, requiring accessible mental healthcare that considers and supports their unique access needs. Other respondents felt that eating disorders are often underestimated and not taken seriously by NDIS Planners. Respondents called for the NDIS to acknowledge the need for disability support to extend to ensuring accessible health and mental healthcare.

> “My plan effectively ignores the ED even though it has a significant impact on my functioning and is related to my physical and psychosocial disabilities.”

One respondent mentioned accessing a psychosocial recovery coach through an eating disorder organisation. This highlights the potential for recovery coaching to be included as part of NDIS supports, which can provide additional assistance and guidance to individuals with eating disorders. Other respondents also described positive aspects associated with access to psychology, dietetic and/or occupational therapy supports. While the positive aspects mentioned above are notable, it is important to recognize that the data as a whole highlights significant gaps and challenges in the NDIS engagement for people with eating disorders. These positive aspects should be seen as areas where progress can be made, rather than comprehensive solutions to the existing issues.

Carers

“We couldn't get funding for a nutritionist for my daughter on the NDIS, even though eating is one her greatest daily challenges.”

Among the carers who completed the survey, there was substantial concern about the impact of feeding issues on mental health, and the complex interplay of these issues with other co-occurring conditions. One respondent mentioned the inability to secure funding for nutritional support through the NDIS, despite the significant impact of eating difficulties on their child's daily life. Carer respondents also called for the NDIS to acknowledge the co-occurrence of eating disorders and Autism in many autistic individuals, arguing that treating an eating disorder in the context of Autism requires a comprehensive approach that addresses the unique needs of Autistic people alongside other common co-occurring conditions such as anxiety.

Two carer respondents mentioned accessing eating disorder support from psychologists, dietitians, and occupational therapists through the NDIS, echoing the comments from people with direct experience of NDIS engagement outlined above.

“[There needs to be] acknowledgment of current research that shows that many autistic people also have eating disorders and it is difficult to separate the symptoms. Inflexible thinking, need for routines and structure, control and anxiety that come with ASD make treating an eating disorder so much more challenging. NDIS needs to acknowledge that you cannot support one without supporting the other. It is ridiculous to provide NO support for psychology for anxiety that directly comes from ASD and is a major contributor to the eating disorder.”

Health professionals

“I am an OT and I have one client with a primary diagnosis of an eating disorder, the remainder of my caseload are all autistic or have a psychosocial disability (no listed ED). I am finding it increasingly difficult for psychological and dietetic support to be funded.”

Health professionals who completed the survey highlighted a lack of clarity regarding what support the NDIS can provide for eating disorders. They expressed a need for better understanding and awareness of the specific supports and interventions available through the NDIS for addressing eating problems. These respondents also expressed increasing difficulties in securing funding for psychological and dietetic support for individuals with eating disorders, as well as difficulties securing necessary supports in a timely manner. The process of accessing funding and recognition for specific conditions, such as

Avoidant/Restrictive Food Intake Disorder (ARFID), was described as difficult and requiring additional efforts. The data from health professionals emphasized the need for coordination of supports and collaboration among professionals to prevent the worsening of symptoms and functioning in people with eating disorders.

Overall, the survey data highlights the need for clearer guidance and information within the NDIS regarding supports for eating disorders. Respondents called for a more comprehensive and inclusive approach to recognize the impact of eating disorders on functional capacity, while also advocating for the integration of disability support with healthcare to address the specific needs of individuals with eating disorders.

> “We need NDIS to acknowledge that disabled people with eating disorders may (and often do) need additional support to access mental healthcare that is inclusive of and adaptable to the access needs of us disabled people recovering from eating disorders.”

Individual stories

Noting the overall negative picture derived from the public survey, NEDC utilised contacts through the project oversight group (i.e. convenience sampling) in an attempt to glean some positive examples of NDIS engagement for people with eating disorders. The purpose of this is to elucidate examples where engagement has worked well, and consider the key success factors and how these may be adopted more consistently.

> The NDIS has benefited me enormously. Not only has it enabled me to sustain therapy, it has assisted me in accessing frequent and regular appointments with my comprehensive team of multi-disciplinary health professionals. This financial facilitation means I don't need to second-guess the validity of each therapist as much which serves me threefold: it gives me peace of mind; it leaves room for HOPE in the potential benefits of further treatment; and it creates the opportunity for the exploration of different approaches in managing my condition. This support has greatly improved my life quality, leaving space for social connection and my passions and interests in life beyond the anorexia. I am convinced that if I didn't have NDIS funding, there would be a greater chance of doors closing for me and the treatment and management of my eating disorder failing or stopping altogether.
>
> For the NDIS to be more eating disorder aware, however, it is imperative I point out that I was accepted only upon a second iteration, in that the first submission from my health professionals focused on my severe anorexia nervosa alone. An NDIS representative explained to me that an eating disorder alone did **not** meet the criteria of a "lifelong and permanent" impairment - NDIS disability requirement 8.2 / NDIA section 24 (1) (b). My health professionals were therefore advised to make a case for permanency on the grounds of Major Depressive Disorder instead, and my psychiatrist amended the first iteration to a diagnosis of *Anorexia Nervosa and Persistent Depressive Disorder*, stating in his recommendation that: *it is of my opinion that (name) suffers from severe and enduring mental illness (and) there is a bidirectional relationship with the eating disorder and Persistent Depressive Disorder.* Given that in spite of suffering from a Severe and Enduring Eating Disorder (SE-ED) such amendments were required to my first submission, I strongly feel that in order to be more eating disorder aware, the NDIS needs to make the diagnosis of an eating disorder a criteria **on its own merit** rather than be dependent on it existing alongside comorbidities.

I'm 51 and have been battling an ED for 35yrs. I am unable to work and rely on the DSP for income. This made outpatient services such as psychology unaffordable and I depended on hospital programs for support when life became too hard. These programs are really not suitable for my age or SEAN diagnosis. My goals are around quality of life rather than recovery.

My first application for NDIS was denied and I discounted it as an option for my condition. However in 2019 I was encouraged by a hospital doctor to try again. This time I had the right reports done with the right wording and I was approved.

Initially I only used funding for practical things such as cleaning and help with shopping.

Then I was put in contact with a support agency that specialised in psycho-social support with qualified workers. This has made a big difference to my life. With their help I was able to organise psychology and dietetic support and use support worker hours to focus on quality of life and connection with the outside world which I had isolated myself from for many years.

My first support worker has now become my mentor (still NDIS funded) and the one on one support has been invaluable. She has been there for me when I needed it and we have made and focussed on quality of life goals.

We have spent 2 x 1 week blocks away together as a form of respite from my normal life when life got hard and this has enabled me to stay out of hospital for 8 months which is my longest spell outside of hospital in a long time. I now feel I have a solid support network around me and am more socially engaged - though I still have a long way to go.

Without NDIS none of this would have been possible and I would likely have given up on therapy.

The application process is long and complicated and getting acceptance of an ED as a disability was and remains difficult but worthwhile when accepted and used in a positive way.

In 2022 I tried to access support from the NDIS for my eating disorder. Despite many detailed letters from my treatment team my eating disorder was classed as a “medical condition” that should be handled by the public health system and not NDIS.

I wasn't provided any funding related to my eating disorder and it was not put on my plan alongside my other mental illnesses.

All my psychiatric conditions are interlinked so despite not getting direct access to services because of my ED I have been able to use services that have assisted my ED recovery.

I was able to see a physiotherapist at the beginning of my ED recovery this was classed for the NDIS to assist my mood however It's primary use was to improve my basic muscle stability after muscle wastage. I've also had access to a psychologist and support workers that have helped my ED recovery as well.

Unfortunately NDIS would not fund a dietitian due to my ED not being on my plan so I have had to find funding privately.

Eating disorders are in the DSM5 they are a psychiatric disability with medical complications not the other way around. Accessing public medical support (as was suggested for me) for an ED is nearly impossible. For someone with other comorbid complex psychiatric conditions, it is impossible for me to get adequate support from the health care system and they probably wouldn't take on my case to begin with.

All of my psychiatric conditions were approved but my ED because of the lack of understanding on what an ED actually is. Given eating disorders have the highest mortality rate of any mental illness they should be receiving the same amount of funding as other psychiatric conditions (as a minimum).

None of my other mental illnesses would be able to improve without adequate treatment for my ED. They are all interconnected and need to be treated that way.

I am lucky that my ED wasn't my primary diagnosis otherwise I would have received no funding and have no access to support.

My journey to the NDIS actually started through seeking help for my eating disorder. I did the Severe and Enduring Eating Disorders (SE-ED) program through Eating Disorders Victoria (EDV) from Feb-Apr 2022. The program was over 12 weeks, where I was provided with many opportunities to talk about the challenges I've faced while living with a SE-ED.

I was formally diagnosed with Binge Eating Disorder (BED) in July 2020. Earlier that year, in April, I was also diagnosed with autism spectrum disorder (ASD). While the diagnoses came when I was in my late 40s, I have struggled with my eating disorder since I was about seven or eight years old. Since beginning treatment for my BED, I have learnt that my eating disorder was likely the coping mechanism I developed to manage living with the confusion of undiagnosed autism.

One of the peer facilitators in the SE-ED program also happens to be a social worker. When I spoke about my day-to-day struggles throughout the program, particularly around the challenges of preparing nutritious meals, the topic of the NDIS was raised. I spoke regularly to the facilitator about the NDIS and whether she thought I might qualify for support. She helped me to understand that the challenges I had around sticking to routines, completing tasks and the relentless fatigue I was experiencing were not character flaws or lack of willpower, but were likely traits of my ASD. It took a while for me to understand that while I had managed to survive in my life, I was struggling to live, the impact of my undiagnosed ASD and decades of using binge eating as a coping mechanism had become an unrecognised, unseen disability.

The process of applying to the NDIS took me more than six months. It's a difficult process as it's so focussed on your worst day and deficits, there were many times that I wondered whether the process was worth it. It was expensive and exhausting. The peer facilitator that I'd met through SE-ED was really amazing in that she was available to listen and cheer me on. Having someone to chat to during the process of gathering evidence was the reason I was able to keep going when it felt too hard.

I finally submitted my application to see if I 'meet access' in late November 2022. I was determined to get an answer before Christmas! In December 2022 I learnt that I had 'met access' which meant I could now ask for the support I needed to begin to live a life rather than survive it.

It took until late March of 2023 before I started to actually receive 'boots on the ground, real world' support. What a difference it has made to my life. I have been able to get a support worker to come to my house and help me prepare meals and clean my house, she has helped me to clear all of the weeds out of my yard and has even helped me start to design an outdoor sensory space! When she comes, we prepare meals for a whole week, she helps me write a plan for the week, including a meal plan and helps me write a shopping list. I used to dread the supermarket, I would forget important things and buy things I didn't need, I was always anxious about how much it would cost. Now, armed with a list and a plan for the week, I know exactly what I need to buy, and can work out how much it will cost before I even get to there. It's much less stressful, if I needed help at the supermarket my support worker would help me with that too but for now, I am able to manage that part of the week on my own.

I've only had the NDIS in place for about four months and already it has helped me to stick to a meal plan because the food is available for me to eat at the time I'm due to eat it. I've managed to go back to work three days a week (I had stopped working in October 2021) and am already starting to plan with my psychiatrist how I will reintroduce gentle movement and exercise into my week. The support through the NDIS has helped me with building a routine and structure that is helping me to eat regularly and adequately. I am starting to believe that not only is recovery from my eating disorder possible but it's happening and I'm learning to live my life, not just survive.

Analysis

When considered together, the policy settings for the NDIS and psychosocial disability, the publicly available participant data, and the survey data and case studies generated to inform this report paint a picture of considerable gaps and inconsistencies, where some positive stories nevertheless also emerge.

Key challenges

One of the significant challenges for those with longstanding eating disorders seeking to access the NDIS is the apparent mismatch between the criteria set out in the NDIS Act, which is the ultimate source of truth regarding NDIS eligibility, and the practical application of Access Lists as a means of excluding people with conditions not on the lists. This is contrary to the intent of those lists, but was consistently raised by members of the project oversight group and echoed in survey data. Clearly, greater clarity is needed as to how the Access Lists continue to be used, and what guidance is provided to the workforce involved in assessing access requests for those applicants whose conditions are not listed. In the context of eating disorders, as the focus of this paper, it seems there is a need for training and other information specific to the potential long-term and life-long functional impacts of this group of illnesses.

Closely related to the above issue is that of the interface between disability services and healthcare provision. While the APTOS sets out a range of supports which could reasonably be provided under the NDIS to a person with a psychosocial disability, it appears in practice that eating disorders may be frequently misunderstood in this regard – two survey respondents spoke specifically about non-disclosure of an eating disorder to their NDIS Planer for fear this may jeopardise access to other support funding. Other respondents spoke of the NDIS failing to recognise the bi-directional impacts of their eating disorder and other condition(s), noting the impossibility of addressing one without the other. While the healthcare system is available to many people with eating disorders at varying degrees of intensity, it is not designed to meet the range of needs that could be met under the APTOS, particularly for those with longstanding eating disorders whose focus may be aimed more towards quality of life rather than treatment. Again, this points to a need for clarity in guidance provided to Planners and Local Area Coordinators, as well as to providers of psychosocial supports.

A third point is the likely under-identification of eating disorders within the NDIS Participant population. This derives from several factors, including systems which do not facilitate data capture, a workforce insufficiently knowledgeable about the relevance of eating disorders to a person's overall functioning, and reported instances of deliberate non-disclosure by Participants (not able to be quantified for the Scheme as a whole). It is significant that the NDIS serves high numbers of Participants with other conditions which are known to have a high co-occurrence with eating disorders – other psychosocial disabilities such as depression (N=14,797) and anxiety (N=26,842), neurodevelopmental differences such as Autism (N=215,191) and ADHD (N=4,437), and metabolic conditions such as diabetes (N=3933). Based on the number of people with these conditions supported by the NDIS, it seems unlikely that only ninety would also have an eating disorder. This issue is further complicated by the fact that data is only collected about one eating disorder diagnostic presentation (anorexia nervosa), when all eating disorders have the potential to be significantly debilitating (van Hoeken & Hoek, 2020).

Following from this range of challenges is the issue of insufficient support being made available for some participants who have an eating disorder in addition to another condition. Several survey respondents highlighted the experience of being provided allied health supports to meet the needs associated one condition being inadequate to meet the individual person's needs in the context of that person also having an eating disorder. Greater attention is needed to the complexity of such Participants' needs to ensure that their support package includes a level of servicing that can adequately account for the (often bi-directional) impacts of their eating disorder on their other disability and their broader wellbeing.

Key opportunities

For those people who have been able to access the appropriate mix and level of support through the NDIS to meet their needs for their eating disorder as part of their whole picture, the Scheme has made a substantial positive difference. This was shown to some extent in survey data, and reflected strongly in the individual stories provided. While not currently a universal experience for Participants with eating disorders, and possibly not a typical one, such examples serve to highlight what can be possible and what could be further developed.

There is an opportunity for the NDIS to equip its workforce (including those working in partner agencies) to recognise the impact of eating disorders on functional capacity. This includes acknowledging the functional limitations caused by eating disorders as a valid reason for seeking support in its own right for some people with longstanding conditions. It should also include ensuring adequate supports and resources are provided to appropriately respond to and manage complexity for those Participants with co-occurring conditions which include an eating disorder. Recognising the interplay between physical, psychosocial, and functional aspects of eating disorders is crucial for providing comprehensive care and support. All of this could be actioned by a workforce supported by clear organisation-level policies and practices, as well as relevant and recurring professional development.

Health professionals responding to the survey emphasised the need for coordination of supports and collaboration among professionals to prevent the worsening of symptoms and functioning in people with eating disorders. The policy settings exist for the NDIS and the mental health system to work closely together at the local level to plan and coordinate streamlined care for people requiring both mental health and disability services and supports. The implementation could be supported via a range of local mechanisms for planning and interagency collaboration.

There is also an opportunity for better awareness and dissemination of information regarding NDIS eligibility criteria and available supports for eating disorders to help applicants, Participants and carers to navigate NDIS processes more effectively. Providing clearer guidance on available supports for eating disorders could enhance understanding among both applicants, Participants, carers and NDIS staff (and their agency partners). This may support a range of outcomes, including:

- Applicants understanding how to navigate the application process, including sourcing required information ahead of time;
- Participants understanding the kinds of support they can request as part of their NDIS Plan, as well as the kinds of supports they can connect with via other systems;
- Planners and assessors having a greater understanding of how to appropriately respond to a person with an eating disorder, either as a longstanding and likely permanent condition in its own right, or as a cooccurring condition which brings certain complexities;
- Where appropriate, people seeking and receiving adequate supports to meet their needs through the Information, Linkages and Capacity Building arm of the NDIS rather than an individual package.

Recommendations

The following recommendations aim to enhance NDIS access and engagement for people with longstanding eating disorders, as well as for people with eating disorders and cooccurring conditions, through improved recognition of and response to the functional impacts of these conditions, and to promote the provision of appropriate supports to improve the quality of life for those affected by eating disorders within the existing NDIS framework.

- Improve data collection about all eating disorder diagnostic presentations, as either primary or secondary diagnosis.
  - It may be possible for people with other longstanding eating disorder presentations to meet NDIS eligibility criteria with their eating disorder as their primary diagnosis.
  - This data should be collected for people with other primary diagnoses as well, to ensure their full range of needs are being met and any complexity is adequately accounted for in support planning and funding allocation.
- Provide information which clarifies the ways in which a longstanding eating disorder may meet the disability requirements for NDIS eligibility.
  - This may include providing case study examples of how an eating disorder can impact daily functioning, e.g. mobility impacts from physical weakness, learning impacts from cognitive effects of malnutrition, social and employment impacts from debilitating body shame, etc.
  - Information should be made available in formats which assist Planners and Assessors, as well as formats which meet the needs of prospective applicants to the Scheme and their carers, including relevant accessibility and cultural considerations.
- Improve eating disorder awareness among the NDIS workforce (including agency partners).
  - Develop and deliver training and other relevant practice resources which support improved awareness of the diversity and complexity of eating disorder presentations and their functional impacts.
  - Ensure supervision and consultation is available for personnel involved in assessing access requests and developing NDIS Plans, either within the organisation or through a third party such as the state-wide eating disorder service development organisations (where these exist).
- Investigate mechanisms for improved local coordination of the disability-health interface.
  - This may include involvement of Local Area Coordinators, Information Linkages and Capacity Building providers, Primary Health Networks and others.
- Integrate disability services within the eating disorders stepped system of care.
  - This involves positioning services provided through the NDIS alongside other social and community services in providing crucial psychosocial supports to enhance overall quality of life for people with eating disorders.
  - The National Eating Disorders Strategy 2023-33 includes specific standards and actions to build and strengthen the psychosocial support workforce, which ought to include relevant sections of the disability sector workforce.

    - The National Eating Disorders Strategy 2023-33 also includes specific standards and actions to build collaborative and coordinated approaches between the health, mental health and psychosocial support interface, which ought to be implemented in this context.
- Monitor and evaluate progress.
    - Establish mechanisms to monitor and evaluate the implementation of the above recommendations, including regular data collection and analysis on NDIS access and engagement for people with eating disorders.
    - Seek feedback from people with eating disorders, their carers, health professionals and others on their experiences with the NDIS and identify areas for improvement.
    - Regularly review and update the recommendations based on new evidence, emerging needs, and feedback from stakeholders.

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