Preliminary Considerations: NDIS supports for weight management

Prepared by: Technical Advisory Branch

1. Issue

1.1. Currently, NDIS legislation and guidance does not effectively address how weight management supports associated with particular disability types and health conditions factor into reasonable and necessary considerations. The disability related health supports (DRHS) policy has actually drawn further attention to the matter through blurring the funding responsibilities for chronic health conditions and preventive health, as established in the NDIS Supports for Participants Rules 2013 (7.4, 7.5) and COAG Principles to Determine the Responsibilities of the NDIS and Other Service Systems - Health table.

1.2. See Appendix A for explanation of how weight management supports are not addressed in current legislation and guidance.

2. Purpose

2.1. The purpose of this paper is:

2.1.1. To provide a preliminary snapshot of the considerations that the NDIA need to make going forward to support NDIS participants who have complex weight-related disability and health care needs.

2.1.2. To present initial suggestions for a policy position to clarify under what circumstances NDIS funding may be used by participants to assist them with managing their weight issues, noting that there are a substantial number of NDIS participants that will require **weight management supports that are directly attributable to their disability**.

3. Recommendations

3.1. As this policy issue permeates across the workloads of multiple business areas, and also carries a significant level of risk, the key recommendation being put forward is that a small NDIA working group is established in early 2020 to clarify these funding and planning considerations.

3.1.1. Working group members will ned to be considered from the following teams: Scheme Policy, Planning Support, Operational Policy, Legal, Actuary, Technical Advisory, Early Childhood Early Intervention, Mental Health and Community Mainstream Engagement (possibly others).

3.2. This paper should be considered a starting point. The issues discussed will require further refinement, troubleshooting and endorsement. The working group will need to:

3.2.1. understand the key issues and risks (legislative, financial, risk to participant etc.) associated with funding these supports;

3.2.2. develop a clear policy position on NDIS supports for weight management supports that is aligned to current policy, particulry DRHS and Attribution policies; and

3.2.3. determine a clear pathway forward to communicate this position to key stakeholders and initiate any service delivery changes as required (e.g. price guide, practice guidance).

4. Key considerations

4.1. Note: For the purpose of this policy proposal:

4.1.1. **Weight management supports** refers to supports that are required by a NDIS participant to manage their **obesity or underweight condition** that are directly attributable to their disability, and causing significant functional impairment. However the main requirement for this policy is to address obesity, as delegates are more likely to receive requests for supports relating to this health condition.

4.1.2. Body Mass Index (BMI) is used to determine weight status for adults – overweight (BMI 25-29.9), underweight (BMI <18.5) and obesity (BMI >30). There is a separate BMI calculator for children (2-20 years) which factors in age. BMI calculators are indictaive, not a diagnostic tool.

4.1.3. Overweight, underweight and obesity are considered health conditions, rather than disabilities, noting all may result in functional impairments.

4.1.4. Overweight is intentionally excluded from these policy considerations. Being overweight is a common health condition that many Australians experience and , and providing supports to prevent or manage health conditions is not a NDIS responsibility (s34.1.f).

4.2. In 2017-18, the Australian Bureau of Statistics' National Health Survey showed that two thirds (67.0%) of Australian adults were overweight or obese (12.5 million people), an increase from 63.4% in 2014-15. Slightly more than a third (35.6%) were overweight and slightly less than a third were obese (31.3%). Just under one third (31.7%) were within the healthy weight range and one percent (1.3%) were underweight[1]. The National Health Survey also indicated that almost one quarter (24.9%) of children aged 5-17 years were overweight or obese in 2017-18 (17% overweight and 8.1% obese)[2].

4.3. These statistics highlight how common these weight related conditions are for all Australians and how important it is that the NDIS does not inadvertently absorb costs associated with managing and preventing these conditions, when circumstances make these health intervention supports more appropriately self-funded, or funded through other service systems.

4.4. This proposed 'NDIS supports for weight management' policy acknowledges that:

4.4.1. There are a considerable number of NDIS participants who will require weight management supports that are directly attributable to their disability.

[1] Australian Bureau of Statistics, National Health Survey: First Results, 2017-18, Overweight and Obesity, 4364.0.55.001, https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4364.0.55.001~2017-18~Main%20Features~Overweight%20and%20obesity~90, accessed 29 November 2019.
[2] Department of Health, Australian Government, 'Overweight and Obesity', 19 June 2019, https://www1.health.gov.au/internet/main/publishing.nsf/Content/Overweight-and-Obesity, accessed 8 November 2019.

4.4.2. NDIS participants with disability related weight issues will likely require different types of support to assist with weight management, during different stages of their life e.g. dietetics, exercise physiology, early intervention behaviour supports.

4.5. Consequently, this policy position will need to make unique considerations for three key age groups:

4.5.1. **Early Childhood 0-7 years**

4.5.2. **Adolescent 8-18 years**

4.5.3. **Adult 18+ years**

4.6. It is also important to note that a perceived correlation or commonality between a specific disability type and being overweight or underweight, does not necessarily imply causation. Many factors contribute to a person's weight status.

4.7. Similarly, just because a NDIS participant has an obese or underweight health status does not automatically mean their weight management supports will be most appropriately provided by the NDIS.

4.8. Acknowledging: 1) the objectives of the Scheme, 2) the insurance based approach focussing on early investment and intervention to improve outcomes for participants later in life and reduce longer-term costs, and 3) Scheme sustainability, it is important that this policy determines the line between supporting NDIS participants to reach a healthy weight to reduce associated functional impairment, and replacing public health treatment and prevention service responsibilities.

4.9. There are two causative scenarios where reasonable and necessary considerations need to be distinguished:

1. **NDIS weight management supports may be reasonable and necessary:** The participant's disability directly causes obesity/underweight status and in turn, their weight status causes or exacerbates functional impairment(s), resulting in further disability.

2. **NDIS weight management supports <u>not</u> reasonable and necessary:** The participant's health condition or lifestyle choices causes obesity or underweight status, and in turn causes or exacerbates functional impairment(s), resulting in further disability.

4.10. One is a disability related issue, while the other is a public health issue.

4.11. The Agency need to consider the obesity or underweight status of NDIS participants holistically, as part of their broader DRHS needs, paying particular attention to:

4.11.1. Functional impact of disability

4.11.2. Genetics and phenotypes

4.11.3. Family context/function/lifestyle (noting for a young child this would be difficult to assess as a factor for obesity)

4.11.4. Medication side effects, particularly for pyshciatric medication where there is a established link to weight gain.

4.11.5. Other social determinants of health

4.12. The determination comes down to the participant's capacity to self-regulate their weight and whether their disabilty impairs them from doing so.

4.13. This approach is consistent with the 'whole of person' approach that the DRHS policy is based upon. Weight management supports could be considered an addendum to the DRHS.

4.14. For some participants these are supports that we would fund anyway e.g dietetics [expand]

5. Work conducted to date

5.1. The Technical Advisory Branch have conducted preliminary literature review into 'syndromic obesity'[3] and the causative link to disability. Available research clearly demonstrates that several health conditions or syndromes have a genetic or metabolic predisposition to weight gain.

5.1.1. These include: Prader-Wili syndrome, Bardet-Biedl Syndrome, Alstrom syndrome, WAGRO syndrome, Albrights Hereditary Osteodystrophy, Fragile X syndrome and Down syndrome. Additionally, approximately 15% of people with Autism Spectrum Disorder (ASD) have a genetic deletion that is confirmed to increase likelihood of obesity. There is also a strong causative link between psychotropic medication usage and uncontrollable weight gain.

5.1.2. The literature review also indicates that for many of these disability types, early intervention in childhood to prevent weight gain and/or undesirable eating behaviours from developing is the most effective support method.

5.2. While likely to be less common than obesity (based on ABS data), there are some NDIS participants who will also have issues with malnutrition and underweight, which are directly attributable to their disability.

5.3. The Technical Advisory Branch also conducted a literature review into the most effective weight management interventions so that delegates are well resourced to make effective and beneficial having regard to current good practice determinations (s34.1.d).

5.4. While there are numerous weight management interventions available to the Australian population, different types of supports have varying degrees of evidence to substantiate that they are 'effective and beneficial'.

5.5. The National Health and Medical Research Council (NHMRC) provide the Clinical Practice Guidelines for the management of overweight and obesity in adults, adolescents and children in Australia (Clinical Guidelines).

5.6. Of particular importance to the NDIS, these Clinical Guidelines provide an outline of how physical and developmental factors may contribute to obesity stating that:

[3] *Syndromic obesity is obesity occurring in the clinical context of a distinct set of associated clinical phenotypes [the set of observable characteristics of an individual resulting from the interaction of its genotype with the environment].*

5.6.1. *"Impaired mobility (e.g. due to physical disability, advanced age or obesity) can affect an individual's capacity to adopt a healthy lifestyle and undertake physical activity. People with intellectual or developmental disability are at greater risk of obesity and obesity tends to occur at a younger age among people in this group. If there is no underlying syndrome to explain obesity, then dietary habits, physical inactivity and socioeconomic factors are thought to contribute to the risk"*[4].

6. Early Childhood 0-7 years

6.1. The Technical Advisory Branch have also held preliminary discussions with the Early Childhood Early Intervention (ECEI) team as it was identified early on that this policy will have the most significant implications for this age cohort.

6.2. The ECEI team have highlighted several considerations for children under 7 years:

6.2.1. Not all children have a clinical diagnosis that clearly identifies a causal link to obesity.

6.2.2. Children with a developmental delay (no diagnosis) may have a functional delay linked to obesity. For example:

6.2.2.1. A child with restricted eating habits may choose foods that result in weight gain.

6.2.2.2. A child with physical delays who cannot move with agility, may increase in weight due to inactivity.

6.2.2.3. A child with sensory sensitivities may select foods that are soothing or stimulating to their senses which results in weight gain.

6.2.3. There may be situations where it is identified that a child might be at risk of obesity if their nutritional intake is not altered to become more balanced. Early Intervention (EI) would be appropriate in this instance - such as dietetics support.

6.2.4. Children under 7 years of age with a diagnosis may experience obesity due to functional delays related to their disability diagnosis. For example:

6.2.4.1. A child with Cerebral Palsy who has physical disabilities may experience obesity as a result.

6.2.4.2. A child with ASD may gain weight due to their rigid preferences for activity and/or food.

7. Adolescent 8-18 years and Adult 18 + years

7.1. As with early childhood participants, adolescent and adult participants will have different weight management support needs due to what the most effective interventions are for their specific circumstances.

[4] National Health and Medical Research Council, *'Clinical practice guidelines for the management of overweight and obesity in adults, adolescents and children in Australia'*, Department of Health Australia, 2013, p.10.

7.2. For participants in the adolescent and adult age cohorts, their diagnosis is now likely known so the functional impairment can be understood. Unless the participant has an acquired brain injuy (ABI) or spinal cord injury (SCI), then the functional impairment may still be unknown.

8. Planning considerations

8.1. As with all DRHS, supporting evidence is required from medical experts or relevant health professionals to clearly explain how the requested support is directly linked to the participant's disability.

8.2. Annual plan reviews will need to assess whether the weight management supports that have been included in the participant's plan are effective. Outcome reports will need to be provided by the prescriber.

8.3. Role of LACs?

8.4. Role of support coorindation?

8.5.

9. Key deliverables

9.1. A clear strategic policy outlining the scope of NDIS funded weight management supports.

9.2. Targeted planning guidance outlining:

9.2.1. Specific considerations delegates need to make for each age cohort.

9.2.2. What supports are effective and beneficial for each age cohort.

9.2.3. Listed diagnosis that will likely result in a NDIS participant requiring weight management supports.

10. Demonstration of Legal Compliance

1.1.1. See Appendix A for explanation of link to legal compliance.

11. Demonstration of Scheme sustainability

1.1.2. The Scheme Actuary has done some preliminary costings in 2018 about the possible impact of chronic health conditions. However these may now be redundant post DRHS policy.

1.1.3. The cost of supporting children likely to be low – rationale from ECEI team?

12. Consultation and Participant centred design

1.1.4. The development of the internal working group will act as the internal consultation process.

13. Risks

13.1. As outlined in the Issue section, current legislation and internal guidance does not account for NDIS funded weight management supports. Consequently there is significant risk associated with not enacting a weight management supports policy.

13.2. The requirement for this policy is to address the risk to scheme sustainability that originates from the lack of guidance for funding of weight management supports.

13.3. While genetics and phenotypes are important and evident for some disability types, (e.g. Prader-Willi syndrome), it is both impractical and undesirable to place too much emphasis on genetics and phenotypes to determine what a reasonable and necessary support is. It is impossible to differentiate whether a physical characteristic such as weight is 100% caused by a person's genotype or whether it is personal preferences, learned behaviours or other social and environmental determinants of health.

13.3.1. There is a risk that if delegates begin to ask participants to provide genetic supporting evidence that more cases will escalate to the Administrative Appeals Tribunal and the Scheme will end up being asked to pay for expensive personalised genetic testing for hearings. Paying for specific medical tests and expert reports is common practice for current hearings.

13.4. Financial risk

13.5. etc

14. Change Management Plan and Communications

1.1.5. A change management plan will be developed once the policy position has been agreed and endorsed.

1.1.6. This will not require external consultation as it is an internal planning guidance matter and will be an addendum to the DRHS policy.

1.2. Implementation Timeframes

1.2.1. There is no critical timeframe to develop and enact this policy, however the longer this matter remains unresolved, and the higher chance that an undesirable precedent in funding weight management supports is set.

1.3. Key dependencies and enablers

1.3.1. This policy position is dependent on the outcome of the attribution policy, costings by scheme actuary and legal advice.

1.3.2. Collaboration between the working groups.

Sponsor: [Insert Name and title – must be General Manager or above]

Prepared by: [Name, Title, Contact]

Attachment(s):

A [Insert title]

Appendix A

Gap in current guidance and legislation re: obesity

In the context of the NDIS and the funding of Disability Related Health Supports (DRHS), disabilities and chronic health conditions that may lead to obesity (directly and indirectly) require further consideration. This is because of:

- the stated 'whole of person' approach that must be taken during NDIS planning; and
- the associated functional impairment(s) that obesity commonly cause.

As outlined in the current guidance, the NDIS will fund a DRHS when it:

- directly relates to a person's ongoing functional impairment, and
- is a regular part of daily life, and
- is most appropriately funded or provided by the NDIS, and
- is evidenced meaning supporting information can generally be obtained.

A DRHS support must still meet the NDIA's legislative framework. As outlined in the DRHS PG:

- The NDIA takes a whole of person approach when funding supports in a participant's NDIS plan. This means that funding for supports is based on the reasonable and necessary criteria in section 34 of NDIS Act and Rules and is *not* limited to the impairments which satisfy the criteria for accessing the NDIS.
- Specifically, in accordance with section 34(1)(f) of the NDIS Act, the NDIA needs to determine whether a disability-related health support for a participant is most appropriately funded or provided by the NDIS.
- The NDIS Supports for Participants Rules 2013, provide that the NDIS is responsible for supports *related to a person's ongoing functional impairment and that enable the person to undertake activities of daily living*, including maintenance supports delivered or supervised by clinically trained or qualified health practitioners, where these are directly related to a functional impairment and *integrally linked* to the care and support a person requires to *live in the community and participate in education and employment*.

The COAG APTOS states that:

- *The above health system will remain responsible for the diagnosis, early intervention and treatment of health conditions, including ongoing or chronic health conditions. This may involve general practitioner services, medical specialist services, dental care, nursing, allied health services, preventive health care, care in public and private hospitals, and pharmaceuticals (available through the PBS).*

This legislation and guidance does not effectively consider how weight management support interventions factor into reasonable and necessary considerations.

Appendix B

Matrix - NDIS funded weight management supports

Causative link to obesity				
Causative link to underweight				
Early intervention indicated				
Age Group	0-7 years		7-18 years	18 + years
NDIS funded supports that would already be included in participant plan				
Additional 'NDIS weight management supports'				
Mainstream supports available for obesity				

Appendix C – Effectiveness of weight management interventions