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National Disability Insurance Agency
GPO Box 700
Canberra ACT 2601

Fragile X Association of Australia submission on NDIS Consultation Paper

Access and Eligibility Policy with Independent Assessments (Nov 2020)

Fragile X Association of Australia welcomes the NDIA's acknowledgement that changes are needed to ensure that the NDIS is simpler and provides consistency in outcomes for participants. We welcome the opportunity to provide comment on the NDIA consultation paper released in November 2020.

About Fragile X-associated disorders

Fragile X-associated Disorders are a family of inherited conditions caused by alterations (CGG repeat expansions) in the Fragile X gene (FMR1) located on the X chromosome. These disorders include a wide range of physical, intellectual and behavioural symptoms that can affect biological family members in different ways. It is estimated that about 90,000 people in Australia are impacted by Fragile X in some way - living with Fragile X syndrome or as carriers of the Fragile X gene premutation.

Fragile X syndrome is recognized as the most common inherited cause of intellectual deficiency. The functional capacity of boys who inherit the gene mutation from a carrier mother is impacted in multiple activity domains. Boys are usually moderately to severely affected with intellectual deficiency and often have severe anxiety regarding social interactions and behavioural disorders as well as autism. Girls can also inherit the gene mutation, but because they have two X chromosomes, they are generally more mildly affected. About 1 in 4,000 males and about 1 in 6,000 females have Fragile X syndrome. Individuals with Fragile X syndrome live a typical lifespan and will have a need for ongoing support throughout their life. There is currently no approved treatment to completely alleviate or cure this disability.

Fragile X-associated Tremor Ataxia syndrome (FXTAS) is a degenerative neurological disorder impacting some carriers of the Fragile X premutation in their later life. FXTAS impacts males more often than females. Its impact on functional capacity across several activity domains is progressive, with onset of severity variable. Symptoms include intention tremor (shaking), ataxia (gait unsteadiness) and cognitive decline.

About Us

Fragile X Association of Australia (FXAA) was established in 1989 and is a member-based national organization serving as the peak body for the Fragile X community. Our mission is to improve the health and wellbeing of those affected by Fragile X. We offer counselling and peer support to individuals and families impacted by Fragile X; provide information and education to the public and professionals in the health and education sectors; raise awareness of Fragile X conditions; and advocate for the Fragile X community.

Our Submission

In seeking the best outcome and experience for NDIS participants affected by Fragile X disorders and their carers, we address the proposed introduction of **independent functional capacity assessments**:

- A. Comments and concerns**
Multidisciplinary assessment; Standardized assessment tools; Appeal process; Choice of assessor; Disability with variable progression.
- B. Feedback on NDIA independent assessment pilot February 2021**
- C. Responses to NDIA Independent Assessment Consultation questions 1, 5-10**

A. COMMENTS AND CONCERNS

1. Multidisciplinary assessment for participants with complex disability

The current NDIS processes allow experts with knowledge of a participant's disability, past supports and support needs across the activity domains to help shape a participant's plan and budget.

The NDIA proposes that an independent functional capacity assessment will be conducted by one suitably qualified health professional for the purposes of informing a participant's access to the NDIS and their plan and budget for supports. The principles underlying the NDIS require that the process will be 'accessible, holistic and strength-based'. Further, the NDIA Independent Assessment Framework states there is "the need to ensure that reliable, high quality, valid assessment tools are used in the NDIS assessment environment." ¹

Our concern is that where disabilities are complex, variable and impact multiple activity domains (for example Fragile X syndrome, and FXTAS), the ability of one assessor to provide a holistic, reliable, high quality and accurate assessment will be limited by their professional training, experience and skill base. Where a functional assessment has been conducted by one health professional, not supplemented with expert opinion, we see a clear risk of incomplete and even inaccurate functional assessments and consequent poor support outcomes for a participant. Further, assessors must be suitably experienced and qualified for the functional capacity assessments they do conduct.

Recommendations:

- *Multidisciplinary assessment:* Consideration of expert reports in addition to the proposed assessment tools for determination of the functional capacity of an individual, with expert reports carrying a defined weighting to form an integral part of the overall functional assessment. Multidisciplinary examples: In Fragile X syndrome: OT, speech pathology, behavioural psychology. In FXTAS: neurology, rehabilitation therapy.
- *Specialist assessors:* trained and experienced assessors with a skill base appropriate for provision of holistic assessments in cases of complex disability, in particular where participants are impacted by intellectual disability and impairment across multiple activity domains.

2. Applicability of standardised assessment tools for participants with Fragile X syndrome

We have some concern that the standardized assessment tools proposed for determining a participant's functional assessment may not be appropriate for assessing the functional capacity of participants who have intellectual disability or developmental delay, for example Fragile X syndrome.

Traditional methods, such as proposed by the NDIA, for generating IQ scores in lower functioning individuals with ID are inaccurate and inadequate due to floor effects, leading to erroneously flat profiles. Symptoms of ADHD are also frequently present, which interfere with accurate assessment. Further, there is a recognized decline between the ages of 6 and 12 in the IQ of males with Fragile X syndrome.

Recommendation:

- More accurate methods for testing individuals who have Fragile X syndrome ² have been developed, which should be considered, and testing problems due to ADHD must also be accounted for to obtain accurate assessments.

3. Appeal process

The NDIA proposes that independent assessments cannot be appealed.

This is not consistent with the ability for a participant or their carer to appeal the outcomes of other elements of NDIS processes.

Particularly in light of vulnerability of participants who have intellectual disability and the risk of incomplete or inaccurate functional assessments in cases where participants have complex disability across activity domains the inability to appeal the result of an NDIA independent functional assessment is a key concern.

4. Choice of assessor: exclusion of assessors providing other services to NDIS participants

The NDIA proposes that individuals who are engaged as independent assessors for the NDIS independent functional assessment process are precluded from providing other services, eg therapies, to those participants.

Where a small pool of expert or appropriate therapy providers exists in a community this restriction will have an adverse impact on NDIS participants. This will have a major impact in regional and rural communities. It will also preclude some condition specific experts from being involved in the NDIS independent assessment processes.

Recommendation:

- Provide flexibility where community circumstances require on the guideline that precludes an independent assessor from providing other services to a participant.

5. Frequency of re-assessment and budget/plan review for progressive/variable disabilities

The frequency of assessment will vary and some flexibility may be needed for progressive conditions including those with uncertain trajectory.

For example: Fragile X-associated Tremor Ataxia syndrome in which mobility and cognitive disability are variable and can decline rapidly.

Recommendation:

- Provide for timing of functional capacity re-assessment as appropriate for the disability and participant.

B. INDEPENDENT ASSESSMENT PILOT FEBRUARY 2021 – FEEDBACK

Where an NDIS participant is a young or adult child who has intellectual disability and multi-domain capacity impairment, such as Fragile X syndrome, the functional assessment process will largely revolve around the parent/carer discussing the daily living functions and supports for the child, the family and other involvement in their care. The carer will respond to the standardized assessment questions.

Recent IA pilot participant feedback from carers in the Fragile X community raises a number of concerns about the functional assessment process. The piloted process is high intensity, high pressure and high stakes for the carer. It is perceived to be the single opportunity for the carer to participate properly, effectively and with full knowledge in the functional assessment for their child, and the consequent NDIA-determined plan and budget.

We have some concerns around the nature of the process and the suitability of the verbal assessment process where carers are vulnerable or require supports, including: ELS, CALD, carers who have intellectual impairment, those with diverse learning needs, older parents, and those parents at risk of anxiety or mental health issues. Research shows, for example, that Fragile X carrier mothers are known to be at increased risk of anxiety, depression and some have executive function deficits, due to the Fragile X gene premutation. ³

Further feedback:

- Undertaking the Q&A and assessment process was described as “draining” and “exhausting and challenging”, involving “hundreds of questions”.
- Questions were put to the carer verbally only: not in advance, and the carer was not able to sight the questions asked by the assessor on the day.
- Some questions were found to be “convoluted or ambiguous” and required verbal clarification from the assessor on a number of occasions.
- The carer therefore found the questions “extremely hard to concentrate on” and the carer “frequently lost focus” which she felt would adversely impact the outcome.
- A concern was raised that assessment questions may cover concepts a carer or participant is unfamiliar with, or be outside a context, eg restrictive practices.
- The carer was extremely concerned that incorrect and incomplete responses would adversely impact the outcome of the assessment and therefore felt under pressure and “like a rabbit in the headlights”.
- The online feedback mechanism on the NDIA website was described as “very, very hard to do and will put a lot of people off”

Recommendations:

- *Length of time of assessment:* Vary assessment times and stages. Plan for breaks.
- *Preparation:* Provide question topics or concepts in advance, with some recommendations or tools that will assist. Eg: diary planner to track number of hours of support needs over time, rather than trying to calculate accurately on the day.
- *Access to questions:* Provide access to questions in advance or on the day in writing/visually.
- *Style of questions:* Ensure questions are clear and well suited to varied communication levels.
- *Feedback:* Seek feedback from participants or carers in a range of formats.
- *Prepare for carers' support needs:* Make provision for those carers of adult participants who also have an intellectual disability such as Fragile X syndrome, and any carers who are elderly and may need additional time or supports in being involved in the functional assessment.
- *Accommodate communication needs:* Make provision for carers who have particular cultural communication or support needs, including access to a translator and material in varied format.
- *Consider mental health aspects:* Take into account that many carers will be anxious and find the process stressful, and structure the process accordingly.

C. INDEPENDENT ASSESSMENT CONSULTATION QUESTIONS

Feedback is provided on several of the consultation questions provided in *NDIS: Consultation paper: Access and Eligibility Policy with independent assessments* at section 4, page 24:

Learning about the NDIS

1. (a) *What will people who apply for the NDIS need to know about the independent assessments process?*

Clearly explain the purpose and outcome of the independent assessment; the options available in where/when and how the assessment is conducted and which supporters can be involved; and how the assessment results shape a participant's budget and plan; explain the next steps.

Provide questions in advance and resources to help participant / carer answer the questions and complete the process.

1. (b) *How this information is best provided?*

In advance in a range of formats that suit difference communication styles and preferences and with CALD and other requirements met.

Undertaking an independent assessment

5. *What are the traits and skills that you most want in an assessor?*

- Empathetic.
- Excellent communication skills.
- Flexible.
- Good listener.
- Experience with disability including intellectual disability.
- Skilled in assessment.
- Aware of and understanding of constraints or concerns the participant or carer may have in undertaking the process.

6. *What makes the process the most accessible that it can be? For example, is it by holding the assessment in your home?*

- The option of having an assessment at home or some other place the participant and carer choose.
- Home can be a good option where the assessment involves a child, with Fragile X syndrome for example, as they will be less anxious, and the parent/carer can have someone else to oversee the child during the process.
- An assessment involving an adult, with Fragile X syndrome for example, may be accessible and provide a more holistic assessment of functional capacity if held partly in their workplace or community setting and partly at home.
- Offer that the carer have a supporter involved in the assessment process to help answer questions and reduce the pressure on the one person.
- Provide the questions, or the context for the questions, in advance or at least during the assessment in a format the participant or carer prefers. The feedback received from carers is that being asked unknown questions for several hours is difficult and challenging.
- Where questions involve calculating the percent of time spent in the NDIS participant's care for example, provide or recommend tools to help estimate this in advance. Eg: diary format.
- An assessor needs to understand any constraints or concerns the participant or carer may have undertaking the process.
- Ensure the assessor is the right fit for the participant or carer. Provide choice of assessor appropriate for cultural and other preferences/requirements, eg gender, age.
- Make provision for additional time/supports for a carer who also has a disability or is elderly.

7. *How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?*

- Deliver assessment in the most appropriate means for the participant/carer.
- Including: communication style which includes graphics, language options, Easy Read, verbal/audio.
- An option to receive the assessment in person, not just post/email.

Exemptions

8. *What are the limited circumstances which may lead to a person not needing to complete an independent assessment?*

Where an individual is unable to engage in the assessment process due to communication difficulties or cognitive impairment and does not have a carer to be involved in the IA in the time required.

Quality assurance

9. *How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?*

Benchmarking over time (where a similar degree of impacted functional activity domain exists)

Audits

Communication with participants

Seek feedback from participants/carers

Communications and accessibility of information

10. *How should we provide the assessment results to the person applying for the NDIS?*

- Summary and full results to be provided in a style that accommodates a range of preferences and abilities, incorporating visuals.
- Option to receive the results by post/email and with point of contact for any questions or concerns.
- Clearly indicate the next steps in the process, e.g. receipt of draft budget and plan.

REFERENCES

1. *Independent Assessment Framework*. NDIA. August 2020. p8
2. *Improving IQ measurement in intellectual disabilities using true deviation from population norms*. Sansone SM, Schneider A, Bickel E, Berry-Kravis E, Prescott C, Hessel D. *J Neurodev Disord*. 2014;6(1):16
3. *Fragile X premutation and associated health conditions: A review*. Tassanakijpanich N, Hagerman R, Worachotekamjorn J. *Clinical Genetics*. 2021; 1-10.

Thank you for your consideration of this submission, and we look forward to hearing the outcomes of the consultation processes.

Yours sincerely,

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