IMPROVING THE NDIS EXPERIENCE: ESTABLISHING A PARTICIPANT SERVICE GUARANTEE AND REMOVING LEGISLATIVE RED TAPE

PARTICIPANT SERVICE GUARANTEE – WRITTEN SUBMISSION

FRAGILE X ASSOCIATION OF AUSTRALIA INC

31 OCTOBER 2019

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BACKGROUND

Fragile X Association of Australia is a member-based organisation and registered charity providing information and support to individuals and families across Australia who are impacted by Fragile X. Fragile X is a family of disorders caused by a mutation on the FMR1 gene on the X chromosome.

These disorders include:

Fragile X syndrome – the leading cause of inherited intellectual disability worldwide and a single gene cause of autism

Fragile X-associated Tremor Ataxia Syndrome – a progressive neurological condition affecting some carriers of the FMR1 gene premutation with symptoms including intention tremor, ataxia, cognitive decline and dementia.

This submission has been based on feedback from carers of NDIS participants who are affected by Fragile X syndrome or Fragile X-associated Tremor Ataxia Syndrome (FXTAS), and are members of our organisation.

This submission is made in response to the *Improving the NDIS Experience: Establishing a Participant Service Guarantee and Removing Legislative Red Tape Discussion Paper*, 2019.

It addresses:

(A) Participant Service Guarantee: Possible Principles for NDIA Service Standards
(B) NDIS Participant Experience, responding to a number of the Key discussion questions

APPENDIX 1

Fragile X Syndrome

- Is diverse and complex in its presentation, therefore the nature of supports is wide ranging.
- Affects both males and females to a varied degree and therefore a "case by case "approach is fundamental.
- Progress for individuals can be slow (mastering e.g. toilet training may take years) therefore realistic goals and an appreciation of the types of supports discussed in planning meetings is key.
- As an inherited genetic condition, an awareness and understanding that multiple family members may be affected by Fragile X to some degree is essential when planners meet with families.
- Some characteristics of Fragile X Syndrome, particularly in females, are not always visible, therefore an openness to understand how an individual is impacted once again requires a level of skill and knowledge by the planner.
- Fragile X Syndrome is a lifelong condition, and whilst interventions, management and treatments may have a significant impact on an individual's progress, there is currently no cure.

Fragile X-associated Tremor Ataxia Syndrome (FXTAS)

- Is diverse and complex in its presentation, and the impacts and severity are variable; the nature of supports required will be wide ranging.
- Onset is in later life (usually 50 years plus) therefore the individual up until the stage of diagnosis most likely will have experienced a full and active life. This is an important consideration when planners meet with individuals.
- An individual's physical and cognitive capacity is severely impacted which in turn may have a significant impact on the health and wellbeing of primary carers also (Another important consideration when planners meet with families to discuss supports).
- The unpredictability and progression of the disability can impact on the length of plan agreed upon and an ability for plan amendment may be helpful

The full text of the 11-page submission from Fragile X Association of Australia is available from the Association by contacting:

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