

The Hon Paul Fletcher MP The Hon Sarah Henderson MP

Minister for Families and Social Services Parliament House CANBERRA ACT 2600

Cc: Hollie Hughes

Dear the Hon P. Fletcher MP and the Hon S. Henderson MP

Subject: NDIS support inadequate for autistic participants

Autism Aspergers Advocacy Australia (A4) observes that NDIS support for autistic participants is often inadequate.

The DSM-5 criteria for autism spectrum disorder (ASD) specify that diagnoses are given only to people who need support. Also, clinicians usually describe ASD, when it is present, as the "primary" disability.

Table E.10 in the <u>NDIS Y6Q1 Quarterly Report</u> shows again that close to 29% of NDIS participants are autistic. Figure E-5 from the report and a similar figure from The Australian (see both figures below) indicate¹ to us that for autistic participants:

- a) the NDIS's target, the "expected average annualised committed support", is about \$37K; and
- b) the NDIS only achieved about \$32K as its "actual average annualised committed support".

A recent article in The Australian suggests that the NDIS scaled back support for autistic Australians to rein in a cost blowout (see <u>Autism support scaled back as NDIS tries to rein in blowout</u>). From the very beginning the NDIS has said it is within budget so clearly there is no cost blowout; nor is there any prospect of a cost blowout while the scheme has so few participants and funding for the largest participant group is "scaled back".

A4 feels that the NDIS target for supporting autistic people is inadequate.

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¹ Estimated from Figure E.5 below because we have not found the actual figure yet, nor has the NDIS met our request for this information.

The current support level is insufficient for either best practice early intervention for ASD or to support autistic adults in their accommodation. Current NDIS supports do not ensure autistic people achieve their goals.

Research and advice to government show that best practice early intervention for an autistic child usually involves a comprehensive program of 20+ hours per week (~1000 hours per year) of intensive individualised ASD-specific therapy for at least 2 years. "Therapy assistants" rather than clinicians can deliver most of the essential therapy but a child's comprehensive early intervention program needs additional and ongoing clinical supervision and administrative coordination (so at \$45.66 per hour², just the therapy component has a bare minimum cost of \$46k per year) – a full early intervention program costs significantly more but delivers substantial saving in the long-run. The cost of effective early intervention for ASD is well above the NDIS's cost target (expected support) for an autistic NDIS participant, so very few NDIS plans provide essential support in the form of best practice early intervention for young autistic participants.

Currently, NDIS planners, with no clinical knowledge or experience, dictate to clinicians how early intervention plans for autistic children will be structured and how funding will be used. The NDIA's existing approach take little or no regard of expert clinical advice, lack essential flexibility and denies autistic NDIS participants the choice and control they are meant to have.

NDIS funding for autistic NDIS participants is significantly worse than these data suggest. Research indicates that 30—50% of autistic people also have intellectual disability. The rate of autistic NDIS participants with intellectual disability may be higher than in the general population as a result of the NDIS eligibility process.

If 30% of autistic participants have intellectual disability and if the NDIS supports intellectual disability³ equitably for autistic participants, then the average NDIS support for ASD as a primary disability is actually \$7.4K (just 23.2% of the support provided is for ASD, 0.3 x 2.56 or 76.8% of the existing ASD support is for intellectual disability).

² This is the rate for a "therapy assistant (level 1)" in the latest NDIS price guide, a remuneration rate that under-pays the work and under-values the skill required for the job. There is a "Specialised Group Early Childhood Interventions - Max Group Of 4" though it is unclear whether the NDIS would allow a group of 1.

³ A4 makes no comment, comparison or judgement about the appropriateness of NDIS support for participants with intellectual disability. Our analysis simply separates supports for ASD from supports for intellectual disability based on information available to us.

If 50% of autistic participants have intellectual disability, then autistic participants with intellectual disability are not funded equitably for their intellectual disability ... and NDIS funding for ASD is extremely limited.

A4 has received reliable reports from the field that participants are registering intellectual disability as their primary disability and their autism/ASD as a secondary disability to improve/increase the NDIS support in their plan. Possibly, they would do better in the NDIS planning process if they didn't mention their autism/ASD at all. The NDIS needs to be better than this.

A4 briefed a member of the Minister's staff on 26/11/2018 about our numerous concerns. A4 is deeply disappointed that the Government has not recognised any of the concerns A4 raised.

Yours sincerely

Bob Buckley A4 Convenor

10/2/2019

Figure E.5 Average committed support by primary disability group (including participants with shared supported accommodation supports) – active participants with initial plan approvals as at 2018/19 Q1 compared with active participants with initial plan approvals as at 2017-18 Q4 (NATIONAL)



