

Dr Helen Nugent, Chairman Mr Robert De Luca, Chief Executive Officer National Disability Insurance Agency GPO Box 700 Canberra ACT 2601

cc: Ms V Rundle, NDIA Mr M Lye, DSS

Dear Dr Helen Nugent and Mr De Luca

Subject: NDIS support is inadequate for autistic participants

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

The DSM-5 criteria for autism spectrum disorder (ASD) specify that a diagnosis is given only to a person who needs 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) indicate<sup>1</sup> 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".

A4 feels that the NDIS target for supporting autistic people is surprisingly inadequate. Question 1: A4 would really like to know how the NDIS a) arrived at its target for its autistic participants, b) justifies this low target, c) feels it is appropriate to decide on such a target without consulting any recognised representatives of the ASD community, and d) consistently fails to reach its support target for autistic participants.

The target may also relate to the "expected funded support levels" matter that A4 <u>raised with Ms Rundle on 2/2/2019</u> ... which Ms Rundle said in a telephone conversation was another website "mistake" and, rather than

<sup>&</sup>lt;sup>1</sup> 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.

engage with stakeholders over NDIS planning and fund allocation matters, the NDIA simply removed the material from its website.

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>). Clearly, there is little chance of a cost blowout when the scheme still has few participants and funding for the largest participant group is "scaled back".

The current support level is insufficient for either best practice early intervention for ASD or to support an autistic adult in supported accommodation. We cannot see how current support could 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. In an evidence-based early intervention program "therapy assistants" rather than clinicians 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. The amount needed 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.

A4 is also concerned that the NDIS funding is significantly worse that this basic data suggests. Research suggests that 30—50% of autistic people also have intellectual disability. As we've indicated previously, we would like to know how many NDIS participants are both autistic and have intellectual disability (as well as their age distributions). The rate of autistic NDIS participant also having intellectual disability may be higher than in the general population as a result of the NDIS eligibility process.

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<sup>&</sup>lt;sup>2</sup> 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.

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).

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.

Question 2: Please provide A4 with figures for the "expected targets" and the average funding levels for autistic participants who also have a) intellectual disability, b) psycho-social disability and c) no other disability (other than being autistic). Question 3: A4 is also interested in the effect of participant age on NDIS support for autistic participants.

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.

Question 4: Please also provide data showing the number of NDIS participants with autism/ASD as a secondary disability broken down by primary disability type.

Please also note <u>A4's established policy and practice regarding</u> unanswered questions.

Yours sincerely

Bob Buckley A4 Convenor

10-02-2019

A4 Autism Aspergers Advocacy Australia

<sup>&</sup>lt;sup>3</sup> 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.

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)



