

The Hon. Mr Dan Tehan MP, Minister for Social Security The Hon Ms Jane Prentice MP, Assistant Minister for Social Services and Disability

Dear Minister and Assistant Minister

Subject: disappointing NDIS response on early intervention for autistic children

Autism Aspergers Advocacy Australia, known as A4, recently received a very inadequate response (MC17-001434) to our emails to you dated <u>5/11/2017</u> and <u>11/12/2017</u>. Our emails to you expressed extensive concerns about the NDIS and specifically its approach to early intervention for autistic children.

Ms Christine Faulkner, General Manager of the NDIS, says: "The Assistant Minister has asked me to reply to you on her behalf".

The result must be so disheartening for you. Ms Faulkner's response to us, on your behalf, is so disappointing for a collection of reasons.

- a) Ms Faulkner revised the goal of the NDIS "to achieve the same outcomes" as the previous disability services system for double the spending. The NDIS was previously meant to improve outcomes. Surely, she isn't allowed to do this.
- b) Ms Faulkner's response ignores all the specific issues relating to the NDIS and its handling of early intervention for autistic children that we raised in our two previous letters.
- c) In the time between our emails and Ms Faulkner's response, the <u>Joint Standing Committee</u> on the <u>National Disability Insurance Scheme</u> (JSC) published its final report from its Inquiry into <u>Provision of services under the NDIS Early Childhood Early Intervention Approach</u> 7/12/2017. The report raise similar concerns to A4's. By not mentioning this extremely relevant report in her response, Ms Faulkner has dismissed its content and implied that your Government and the NDIS have scorned the JSC's report.
- d) Ms Faulkner's response obliterates any hope of the NDIS recognising and addressing A4's concerns about the NDIS's early intervention approach for autistic children. Consequently, the ASD community sees little or no prospect of the NDIS improving on the unnecessarily abysmal outcomes that the Australian Bureau of Statistics observes for autistic people in Australia.

e) Much of the content of Ms Faulkner's response may be seriously inappropriate as discussed in detail in Annex A below.

While the response is dated 20/12/2017, it wasn't sent until 1:18pm on Friday 22/12/2017. Perhaps Ms Faulkner hoped that by the time it reached A4 it would be too late for A4 to respond in 2017 ... but autism affects peoples lives 24 hours per day for 365½ days of the year. A4, autistic people and their "informal carers" are not on a break; they are not taking time off – if anything they are busier at this time while the formal supports take their seasonal break.

Please note also, A4 has not received the promised follow up on the subject of early intervention for autistic children from the letter 20/3/2017 nor any response to its email to NDIA 23/11/2017.

We wish you season's greetings.

Yours sincerely,

Bob Buckley A4 Convenor.

24/12/2017

Annex A. A detailed commentary on the letter

Following is a detailed response to Ms Faulkner's letter. In the letter, Ms Faulkner:

disability sector, and the ASD community in particular?

- 1. says "The National Disability Insurance Agency (NDIA) is committed to ensuring participants receiving supports prior to the introduction of the NDIS are able to achieve the same outcomes under the NDIS" ... but the NDIS was designed to deliver *much more* than the "the same outcomes" as the inadequate outcomes of the previous system. Ms Faulkner has downgraded the NDIS's goals the NDIS needs to achieve *substantially better outcomes* than the previous system. The previous system achieved the same outcomes at half the cost.
 When did the Government downgrade the NDIS's objective? Where is the new objective documented? When were the changes agreed with the
- 2. implies we don't know, because we need to be told or reminded, that "This does not mean the same level of funding or supports will be provided in the same way". The concerns raise in the emails Ms Faulkner is responding to show we have adequate knowledge and experience of the NDIS's operation. This demonstrates little or no respect for the ASD

community. Members of the APS are required to respect others.

- 3. says "The NDIA will seek to identify alternative support options, or make referrals to other systems, with a view to ensuring the same outcomes can be achieved" the "will seek" phrase is very concerning since any identification of "alternative support options" should already be in place. And "the same outcomes" phrase is (as in 1. above) well below the requirement for NDIA performance.
- 4. says "No two NDIS plans are ever the same because no two people's goals or aspirations and individual circumstances are the same". For privacy reasons, there is no way to check such a claim. This is confusing since the NDIS's "introduction of typical support packages which establish a benchmark amount of support for participants with specific characteristics" see COAG Disability Reform Council Quarterly Performance Report 30/9/2017 shows the NDIS operates a system of secret "typical support packages" for people with disability who have similar goals and needs.
- 5. claims "Planners aim to be consistent in their application of what is reasonable and necessary for the NDIS to provide. However, plans are always tailored to the needs of the individual." NDIS JSC's recent findings and recommendations about early intervention shows that even if "planners aim to be consistent" they often fail. A4 and the NDIS JSC agree that plans are not "always tailored to the needs of the individual". Ms Faulkner's claims is false.
- 6. states "The Early Childhood Early Intervention (ECEI) approach supports children aged 0-6 years who have a developmental delay or disability and their families/carers". A4 and the NDIS JSC agree that this statement is not true because the NDIS does not always (too often fails to) support "children aged 0-6 years who have a developmental delay or disability".



- 7. claims "The ECEI approach supports families to help children develop the skills they need to achieve the best possible outcomes throughout their life". There is so much wrong with this claim.
 - a) this claim is contrary to the research evidence on early intervention for autistic children, as the emails Ms Faulkner says she is responding to (and essentially ignored) indicate.
 - b) the advice the NDIA says it based the ECEI Approach on, the National Guidelines, Best Practice in Early Childhood Intervention. But rather than dumping responsibility for early intervention for autistic children on their families as Ms Faulkner suggests, the advice acknowledges "the role of direct intervention by specific professionals" since "there are also other bodies of evidence that suggest specific intervention for children with specific needs, such as ... autism spectrum disorder that lead to improvement in childhood development and skill development". Research and research reviews consistently say autistic children need clinically supervised early intervention "to achieve the best possible outcomes throughout their life". Such outcomes rarely result from dumping responsibility for early intervention on families as Ms Faulkner describes.
 - c) The ECEI Approach, because it focuses on supporting families to try to deliver their own early intervention for autistic children, is not good practice for autistic children. So the ECEI Approach, when applied to autistic children, is contrary to "insurance principles", immorally avoids good practice and may be illegal.
 - d) As the subject is quite technical, A4 doubts Ms Faulkner has appropriate knowledge or experience of early intervention for autistic children that would allow her to make this claim. Nor does she appear to have consulted anyone with an appropriate background or expertise in early intervention for autistic children. A4 wonders whether this remains within the APS Values and Code of Conduct as it denies children their right to treatment, education and prospects for independence and freedom of expression. It diminishes the public's trust in Government.
- 8. claims "There are supports that are unable to be provided under the NDIS, as they are the responsibility of other service systems". It is very clear that early intervention for ASD is an NDIS responsibility; it is not a responsibility of anyone else. It is inappropriate for Ms Faulkner to refer us elsewhere on these issues.
- 9. says "The NDIS will continue to provide community linking and individualised support for people with permanent and significant disability, their families and carers. The NDIA will continue to build relationships with mainstream service providers and the local community. This will improve their understanding about how they can assist people with disability." Early intervention for ASD is a specialised clinical service. Mainstream services providers and the local community have important roles in an autistic child's EI program but they do not provide or replace good practice early intervention for ASD.



10. says "Thank you for bringing your concerns to the Assistant Minister's attention" however she clearly dismisses all the issues raised. She is doing her best to dissuade the Government and its Ministers from addressing the concerns of the ASD community about the operation of the NDIS.

