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YELLOW LADYBUGS SUBMISSION TO: NDIS CONSULTATION ON ACCESS AND ELIGIBILITY POLICY FOR INDEPENDENT ASSESSMENTS

Yellow Ladybugs is pleased to make the following submission to the NDIS consultation process on the 'Access and Eligibility Policy for independent assessments'. In making this submission, we draw on the NDIS experiences of our extensive community of autistic girls, women and individuals, and parents/carers.¹

ABOUT YELLOW LADYBUGS

Yellow Ladybugs is an autistic-led non-government organisation with strong bridges to the community. We are dedicated to the happiness, success and celebration of autistic girls and women. We believe all autistic individuals of all genders deserve to be recognised, valued, accepted and supported in order to realise their full potential. We are committed to shining a light on autistic girls and women through the creation of positive and inclusive experiences for our members and through advocating for the rights of all autistic individuals and celebrating their neurodiversity.

Yellow Ladybugs runs regular informal social events that offer peer-to-peer connections for autistic girls and gender diverse individuals generally between the ages of five and sixteen. Our events bring our members together in an inclusive, fun and sensory-friendly setting. Underpinning every Yellow Ladybugs event, our mission is to foster a sense of belonging for all our autistic girls, to help them connect with their tribe and to instil autistic pride within our community.

We are also committed to changing the common misconceptions about autism, ensuring autistic girls and women are properly supported according to their needs, and building a society that values and empowers all autistic individuals. We actively seek to address the many challenges the community of autistic girls and women face, including barriers to diagnosis, lack of inclusion in school and employment, and access to support services.

Yellow Ladybugs is an inclusive organisation, and while we have a particular focus on autistic girls and women, we recognise all genders and welcome trans and gender diverse autistic individuals into our community. We consider that the different presentations of autism exist as spectrum across all genders, and as an organisation, we seek to dismantle all stereotypes which are harmful to the autistic community. We know that autistic girls and women, and particularly those with hidden

¹ We use identity-first language ('autistic') based on our community's preference. We use the terms 'women' and 'girls' as our key focus, but also support and represent gender diverse autistic individuals. We are committed to building knowledge about the less visible and less understood internalised autistic experience, and which is more common for autistic women, girls and non-binary individuals, but seen in all genders.

needs, continue to be significantly disadvantaged, however, and we remain committed to our mission to reduce these disadvantages.

SUBMISSION: OPENING STATEMENT.

The NDIS consultation paper “Access and Eligibility Policy for independent assessments’ has asked us to consider a number of questions, which we have responded to in more detail below. Over and above this, we would like to take this opportunity to register our strong reservations about a policy which makes independent assessments mandatory. Autistic girls and women (particularly those with an internalised autistic presentation) already experience significant disadvantages in getting their support needs acknowledged through the NDIS process. For many girls and women, these barriers exist even when the autistic individual and their family/carers are able to provide detailed expert reports from paediatricians, psychologists and other allied health professionals. Whilst we understand the initiative to make the assessment process more accessible, we have very serious concerns over a process which sees independent assessors making decisions about complex individuals on the basis of a single meeting.

We also question the claim that independent assessments will ensure the process is fair and equitable, in part by ensuring that bias doesn’t occur where the assessor is overly familiar with, and sympathetic to, the participant. By this same logic, a child’s school report should not be written by their class teacher, because the teacher may be biased in the way they have assessed the child. When we are talking about disabled individuals, with complex, but often hidden needs, we maintain that the assessment of their needs is best made by the experienced professionals who are already engaged, and familiar with, and most importantly, trusted by that individual.

Yellow Ladybugs represents a strong, motivated and engaged community of autistic girls, women, gender diverse individuals and parents, families and carers. Our community members have told us unequivocally that they have very strong concerns about the shift to independent assessments, and specifically that this process will lead to autistic girls and women facing even more barriers than they already do in accessing NDIS support. As a bare minimum, we consider it critical that the NDIS consults deeply and meaningfully on this topic with the actually autistic community. The principle of ‘nothing about us without us’ must be applied, as enshrined in the NDIA’s acknowledgement of the social model of disability, and its commitment to the principles of ‘choice’ and ‘control’ as underpinning the NDIS scheme. **In addition to making this submission, Yellow Ladybugs would welcome the opportunity to represent our community directly with the NDIS as part of the public consultation process.**

RESPONSE TO CONSULTATION QUESTIONS

Learning About the NDIS

1. What will people who apply for the NDIS need to know about the independent assessments process? How this information is best provided?

Accountability is vital and must be communicated at the outset. From the lived experience of our community, accountability is often dismal in the current NDIS planning process. We therefore welcome the chance to rectify this if a major overhaul of the assessment process is underway.

Case study: *“I will say that most planners have been engaged and have understood clearly the support needs we have outlined to them. However on one instance our planner did not understand our message and he did not seek clarification. We could not contact him to*

address mistakes that he had made. He submitted the plan and had it approved and we were told any review would take at least a year. There had been confusion around which line items were self-managed and which were agency managed. On that occasion it was impossible to rectify the plan. Once the plan was approved the only avenue was formal review, despite aspects of the plan clearly being erroneous. I know the review process has recently been streamlined but there still does appear to be a lack of accountability. Contacting those that are making decisions should not be difficult."

Accessing the NDIS

3. How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent and life long?

Autism is a life-long neurodevelopmental disability. It is part of the autistic person's identity and as such there will be no variation in the 'condition' as far as life-long impacts and supports that are needed. Like any disability, the impact may vary day-to-day and year-to-year, but it should be made clear throughout the NDIS process that an autistic individual does not need to constantly prove that they require supports and that their disability impacts their daily life. Once a diagnosis is received and statements are made about how the individual chooses to live their life, it should be understood and explicitly acknowledged that the applicant requires support for their lifetime.

Undertaking an independent assessment

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

Independent assessors would require a very deep level of expertise on autism, including detailed knowledge of the more 'internalised' presentation of autism that is experienced by many autistic girls and women (as well as gender diverse autistic individuals and some autistic cis-males). This means that the assessors will be able to look past the fact that the individual being assessed may present well and appear to be coping, and to understand that their needs, and their disability may be hidden. **It is critical that the NDIS engages with the autistic community, for both training and programme development in relation to the independent assessments policy, as the depth of understanding required is complex and extensive.**

In addition to having a properly informed understanding of the full diversity of the autism spectrum, it is absolutely critical that independent assessors are able to demonstrate compassion. Trauma-informed care should be top priority. This means acknowledging the past trauma of the participant and possibly the carer/guardian. It also means understanding that many autistic children have at least one autistic or neurodivergent parent who themselves may be needing support with the application and interview process. Feedback from our community confirms that these types of interview processes can be triggering for everyone involved. Prior case notes, reports and assessments **MUST** be read by the independent assessors, with no excuses made on that front.

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

This should be driven by the individual and their family/carers needs, and not the assessor. Nobody wants the applicant/participant to become distressed during an assessment. Our concern, however, is that setting the applicant up for a less traumatic interview (e.g., at their home with their comforts and supports) may result in the applicant being told their functional capacity is considered to be average and no supports are needed. And that this assessment is made, on the basis of this single observation, despite previous professional reports which clearly outline the applicant's support needs.

Alternatively, we are concerned that forcing an autistic applicant into an assessment process where they are uncomfortable, and unable to access their usual supports makes it more likely that they have a meltdown or become overwhelmed and agitated. The assessor may then find that supports are needed, but this comes at an unacceptable traumatic personal cost to the individual involved.

We are seeking further clarification on whether these are the two options that participants are going to be forced into choosing between. We also note that even an assessment at home can be very triggering given it's the applicant's safe space – and it is possible that the applicant may both be traumatised by this invasion of their safe space, but still assessed as not requiring support due to the efforts that have gone into supporting them to undergo the assessment in their own home.

Exemptions

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

We would ask that as part of the consultation process, further clarification is provided on the matter of exemptions. There needs to be clear and explicit information on how a person gets an exemption. We consider that if an exemption can be given for safety purposes, this should include extreme distress. Further information is needed on what documentation is requirement for an applicant to be exempt, and on who is responsible for reviewing and deciding on exemptions.

We provide the following real life case study as an example of where an exemption from the independent assessments process clearly needs to be agreed to. This case study also highlights our deep concern over the potential for inexperienced assessors to cause extreme distress and lifelong trauma in the child or individual being assessed. Duty of care and the principle of 'do no harm' must be at the front of this process, and if this cannot be guaranteed, then any individual at risk of trauma and extreme distress must be allowed on exemption.

Case Study: *When my child was being assessed for eligibility 4 years ago. This was our initial assessment when we originally applied for NDIS. We were told we had to have an independent assessment and that this was to be done in our home so that the assessor could meet the family and see our household. When the assessor arrived she was very engaging and she did attempt to make my daughter (the applicant) feel relaxed. Despite her best intentions when discussing the functional capacity of my 8 year old child, doing this in the presence of my child was triggering for her. Our child quickly became very distressed and agitated. She rapidly escalated into unsafe behaviours including risk taking and self-harm*

(smashing glass and walls etc). At the time I was home alone with my two other younger children who also became very upset and distressed. Our eldest child (the applicant) continued to escalate and she wanted the assessor to leave. The assessor ended up physically restraining my child on the floor while I tried to calm my other children. This was a sitting restraint and went on for about 45 minutes. This particular worker advised my child that she was from the government and that she would not leave until she deemed that the family where no longer at risk and that she had to calm down before she would be let go. At the time I wasn't actually even sure what powers the assessor had. I wasn't sure if she was going to engage the police as she had deemed my other children at risk from the escalated behaviours. I wasn't sure if we would be rejected for our NDIS entirely if I asked the assessor to leave or stop. This is not a personal attack on the assessor but highlights the complexity and risks associated with making independent assessments compulsory. We really had no information prior to the meeting about rights and obligations. I was told by the assessor that she was a contract worker who was only working on the implementation of NDIS. I was unable to contact that worker again. It is fair to say all involved have trauma from this event – the participant, me and my other children.

The result of this traumatic assessment was a decent NDIS package but was it really worth the trauma? I'm extremely concerned that my child might be forced to do another assessment with this history documented. At what point do we say you do not need to SHOW me a distressed child or individual and instead that I will take your evidence of the fact?"

Quality assurance

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

Open and two-way communication is a must. The independent assessor should be delivering their message directly to the applicant and their family/carers. This communication must be direct and not hidden behind letters and reports. If the independent assessors are going to make sweeping assessments based on a short observation period, then as a bare minimum, they should be easy to access directly to ask questions if needed.

We also consider that if any assessor receives more than three complaints they should be suspended until a review can be completed. There needs to be some boundaries, and protections for the applicants and their families, who are already vulnerable due to their disability. We are concerned by the potential for the independent assessors to have complete power, with the applicant having no proper recourse.

Communications and accessibility of information

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

Applicants or parent/guardian need to be asked how they prefer assessment results to be delivered. Many people within our community would probably prefer a report to be sent first allowing processing time. Followed up by a phone call or meeting if queries need to be addressed or if the applicant wants the assessment reviewed.

The best practice principles of open two-way communication should always be applied, and this is best achieved through a DRAFT review process, where the assessor delivers a draft report for feedback before the report is finalised. If the process is to be truly transparent we should allow for fair discussion and open of the assessment points prior to submission.

Yellow Ladybugs is proud to advocate for the rights of autistic girls and individuals, and we would welcome the opportunity to participate further in the NDIS consultation process on Access and Eligibility Policy for Independent Assessments