

## Consultation Survey

### Feedback on draft NZ Autism Guideline Supplementary Paper on sex/gender differences in the presentation of autistic characteristics

We are grateful for your time and contribution to this important update to the Aotearoa New Zealand Autism Guideline – He Waka Huia Takiwātanga Rau (2022)

Please enter your responses below (*add more space as required*). The deadline for participating in this sectoral consultation is **5pm Friday, 12 April, 2024**

#### 1. Are the Recommendations and Good Practice Points **clear and well worded**?

Generally, our subject matter experts (SMEs) considered the recommendations and good practice points to be clear and well worded. However, we note that GPP 1.2.14b is quite long and includes two slightly different points (two separate sentences). For clarity, our subject matter experts suggested that this point might better be split into two points, under the same recommendation heading.

#### 2. Do the new Recommendations and Good Practice Points appear **valid** (based on the reviewed research)?

Generally, our SMEs considered the recommendations and good practice points to be valid, based on both the reviewed research and our own clinical experience. However, we were relatively unconvinced by GPP 1.2.14d “An autistic-friendly environment for assessment should be provided to minimise the need for autistic masking.”

While we would completely agree with the first clause “An autistic-friendly environment for assessment should be provided”, we’re not convinced that there is any evidence to suggest that doing so would reduce a person’s masking (in an assessment environment). This clause does not appear to flow directly from the evidence, so you may wish to consider whether it is useful to include it.

3. Are the proposed Recommendations and Good Practice Points **relevant** and **applicable** to sectors of the community you engage with?

Generally, our SMEs considered the recommendations and good practice points were relevant and applicable to the sectors of the community in which they work. However, the broad nature of the recommendations (and the accompanying research review) will make them difficult to operationalise in practice (see below).

4. Are the proposed Recommendations and Good Practice Points **able to be implemented** (are there realistic expectations for them being applied)?

As above, the recommendations and GPPs are highly positive and validated our SMEs' experiences in practice. However, the very small effect sizes in the research, across very broad categories, makes them potentially difficult to apply in practice. One of our SMEs asked the question "how would you measure whether a service was or was not implementing these recommendations?", which we believe points to their relatively vague nature. With the research as it is, it may not be possible to make more concrete recommendations at this stage.

5. Do you have any **other comments** or suggestions about how we can improve this Supplementary Paper?

Our SMEs felt that the following sentence, on Page 10, was quite misleading:

"Characteristics of autism can generally be seen before 12 months of age, with a stable clinical diagnosis possible around 18-24 months [68]"

The term "generally" appears to imply that it could be possible to identify all people with autism by 12 months of age, however we do not believe that the evidence would support this view at all. Furthermore, the second clause is based on a relatively small study (68), which only identified that the diagnosis was 'stable' around 1 year later - there was no follow up beyond the age of 36 months. While it is *possible* to (correctly) identify *a proportion* of autistic people within the first 12 months, we do not feel it is correct to suggest that this is the norm.

6. Can you suggest **other topics/areas** that need to be **updated** in the Aotearoa NZ Autism Guideline and why? (e.g., new research, current Recommendations no longer apply, gap in the current guideline)

Our SMEs suggested that it may be time to review the topic of Applied Behavioural Analysis, as the existing guidance was developed in 2010 and much of our thinking around autistic behaviour has moved on.

7. Any other comments?

Thank you for the opportunity to comment on this guideline. The review has been well managed and is of a high quality and the recommendations are well-considered. We would certainly support their implementation, taking into account the above feedback.

**Name:** Dr Paul Skirrow (on behalf of several members)  
**Email:** paul.skirrow@otago.ac.nz  
**Organisation:** New Zealand College of Clinical Psychologists  
**Relevant expertise or role:** All of our SMEs are clinical psychologists working with people on the autism spectrum/neurodiversity. Paul was a former specialist in autism in the UK and his research work has been included in autism guidelines from NICE (CG142/CG170) and the US Department of Health and Human Services (2017).

## Thank you

Please return the completed questionnaire to Marita Broadstock (Autism/Takiwātanga Living Guideline Manager) at this email address: [maritabroadstock@insightresearchltd.com](mailto:maritabroadstock@insightresearchltd.com)

Responses are due by **5pm Monday, 8 April, 2024**