

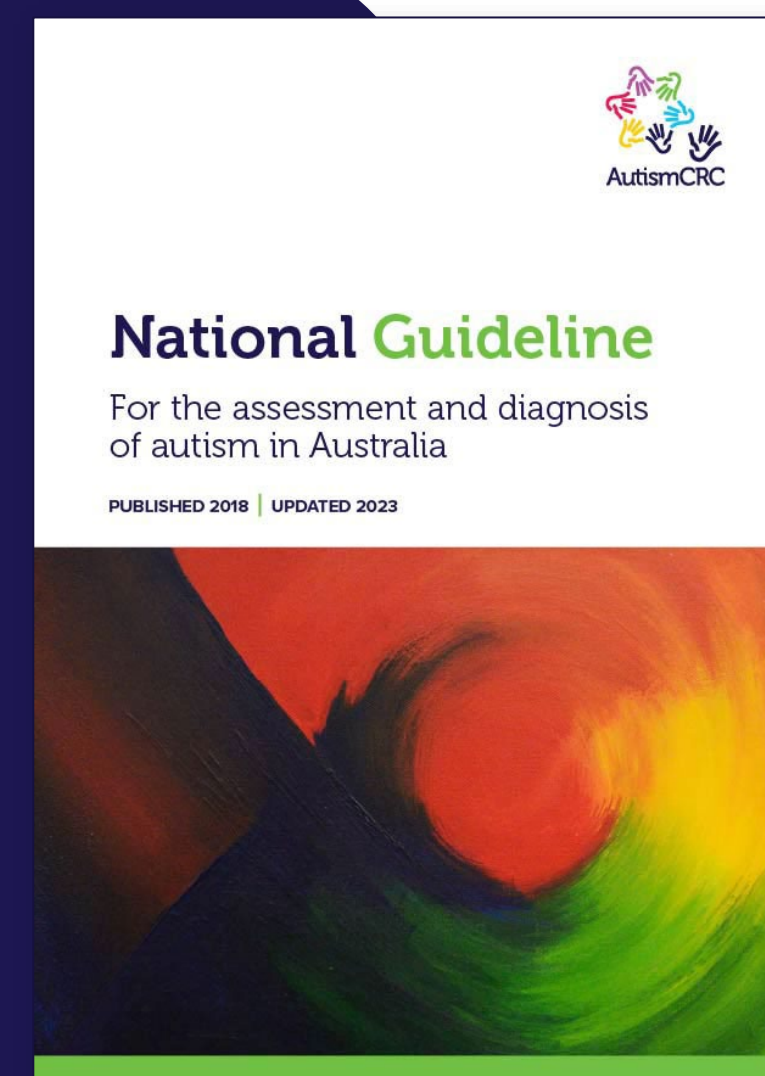
Community Views on the Assessment and Diagnosis of Autism: Principles to Guide Clinical Practice

Rhylee Sulek^{1,3}, Rachele Wicks^{1,3}, Emma Hinze¹, Nicole Dargue^{1,2}, Briohny Dempsey³, Emma Goodall^{1,4}, Libby Groves¹, David Trembath^{1,3}, Hannah Waddington⁵, Andrew Whitehouse^{3,6}, and Kandice Varcin^{1,3}.

¹Griffith University ²Autism Centre of Excellence, Griffith University ³Telethon Kids Institute ⁴Autism South Australia ⁵University of Wellington ⁶University of Western Australia

Study aim:

To explore the experiences, views, and perspectives of members of the autistic and autism communities in Australia regarding the assessment and diagnostic process, specifically in relation to practice principles which seek to improve the quality, consistency, and accuracy of services provided to autistic individuals and their families.



Background

- While the diagnostic label of autism in and of itself can be informative, it is insufficient to inform individual priorities and support needs.
- Instead, practitioners must conduct a comprehensive assessment to determine an individual's strengths and challenges as a foundation for appropriate, safe, and effective supports that are meaningful to the autistic person and their family (where appropriate).
- However, due to policy and system level factors, including the availability of funding for supports, receiving a diagnostic label is often the primary outcome of assessment in Australia.
- In response to the dissatisfaction often experienced by autistic individuals and their families when going through the assessment and diagnostic process, it appears timely to identify key principles to guide best practice at each stage of the process.

Method

- This study drew from a broader set of co-designed research activities aimed at exploring community experiences, views, and perspectives of the assessment and diagnostic process for autism in Australia.
- Autistic individuals, family members, practitioners, and organisations who provide assessments and diagnostic services (n = 871) participated in an online survey and series of focus groups.
- This study focused on a subset of questions qualitatively analysed using the Framework method of analysis.
- Participant responses were coded in NVivo according to a coding protocol that was constructed from a subset of initial online survey responses (n = 100).

Results

- A total of 3 overarching themes, encompassing 15 codes, were constructed from participant responses across groups.
- These represented the principles that should underpin practice across the assessment and diagnostic process.

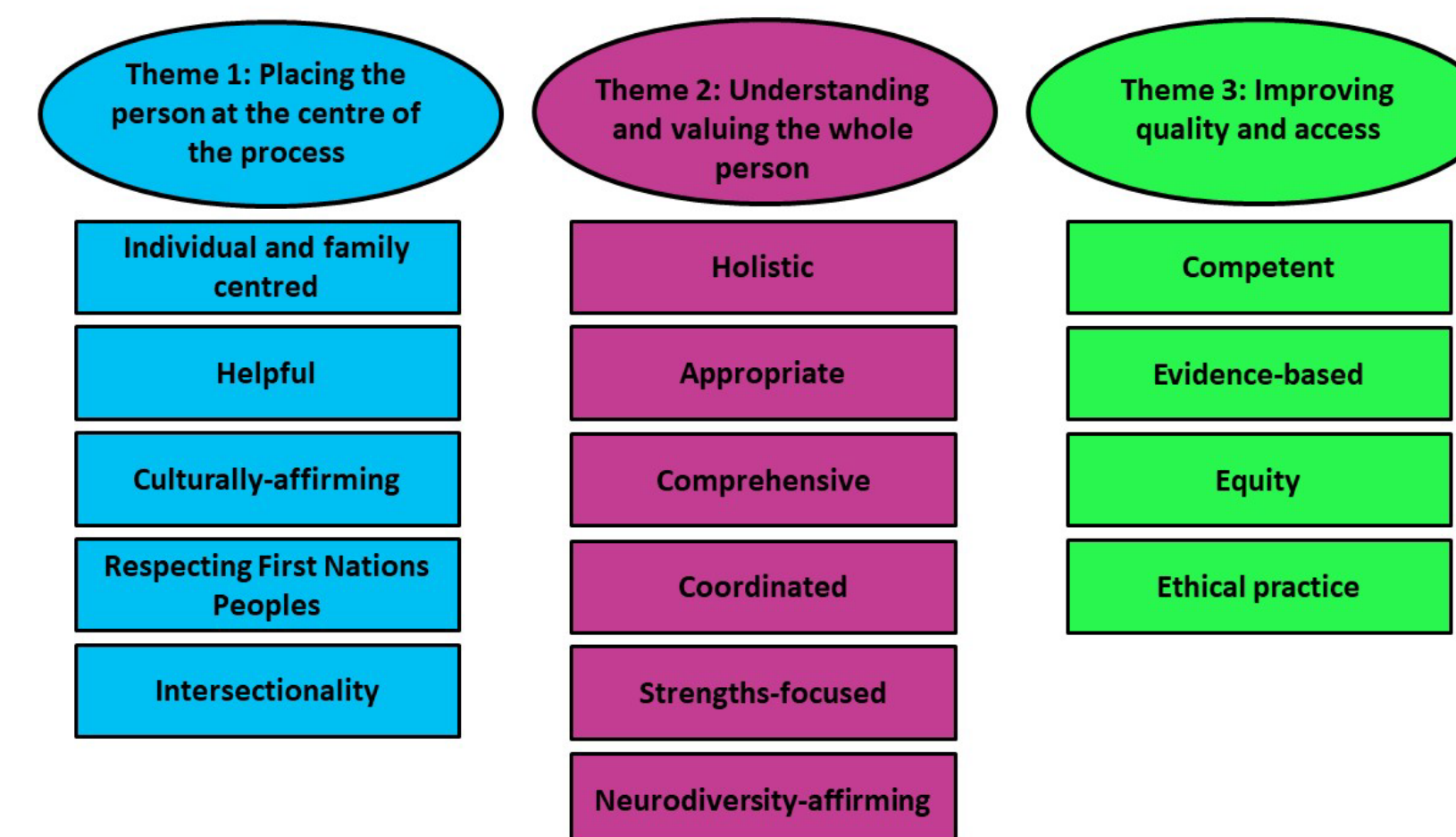


Table 1: Responses per principle code across participant groups

Principle codes	Total per Principle across participant groups					
	Autistic person	Family	Practitioner	Organisation	Other	Total
Appropriate	172	170	155	62	26	585
Competent	207	268	244	102	43	864
Comprehensive	65	113	158	44	21	401
Coordinated	31	58	84	24	4	201
Culturally safe	8	9	6	11	2	36
Equity	164	216	124	42	19	565
Ethical	30	18	38	18	5	109
Evidence-based	48	89	118	37	20	312
Helpful	183	217	136	77	23	636
Holistic	127	132	118	55	20	452
Individual and family-centred	107	146	79	53	26	411
Neurodiversity-affirming	92	77	97	53	13	332
Respecting First Nations Peoples	3	3	3	3	2	14
Strengths focused	64	81	87	26	10	268
Other	151	176	160	79	34	600

Implications

- In the Australian context, this information has informed the update of the National Guideline for the Assessment and Diagnosis of Autism (2023) and reflects the importance of co-designed research with the autistic and autism communities.
- For practitioners and researchers outside of Australia, these principles may guide new research to inform best practice for the assessment and diagnosis of autism in local contexts.

Conclusion

It is increasingly recognised that the assessment and diagnostic process for autism needs to go beyond diagnostic decision-making to also include an understanding of individual needs and identification of pathways to better support immediate, and longer-term outcomes for autistic people. As highlighted by participants, several principles should guide how practitioners approach the assessment and diagnostic process and engage with individuals and families receiving their services. This is important to ensure that assessment for autism is conducted in ways that promote best practice, reflect the perspectives of autistic people, and engender meaningful outcomes for individuals and families that are independent of receiving a diagnostic label.

For more information

Dr Rachele Wicks | Phone: +61 0416047239 | Email: r.wicks@griffith.edu.au

The authors acknowledge the financial support of Autism CRC, which was established under the Australian Government's Cooperative Research Centres Program.

autismcrc.com.au
[@autismcrc](https://twitter.com/autismcrc)

