



Autism/Takiwātanga Diagnostic Processes in New Zealand

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Why did we do this research?

“Cost for private diagnosis is too high”

“Diagnosis through the public system involves long waitlists”

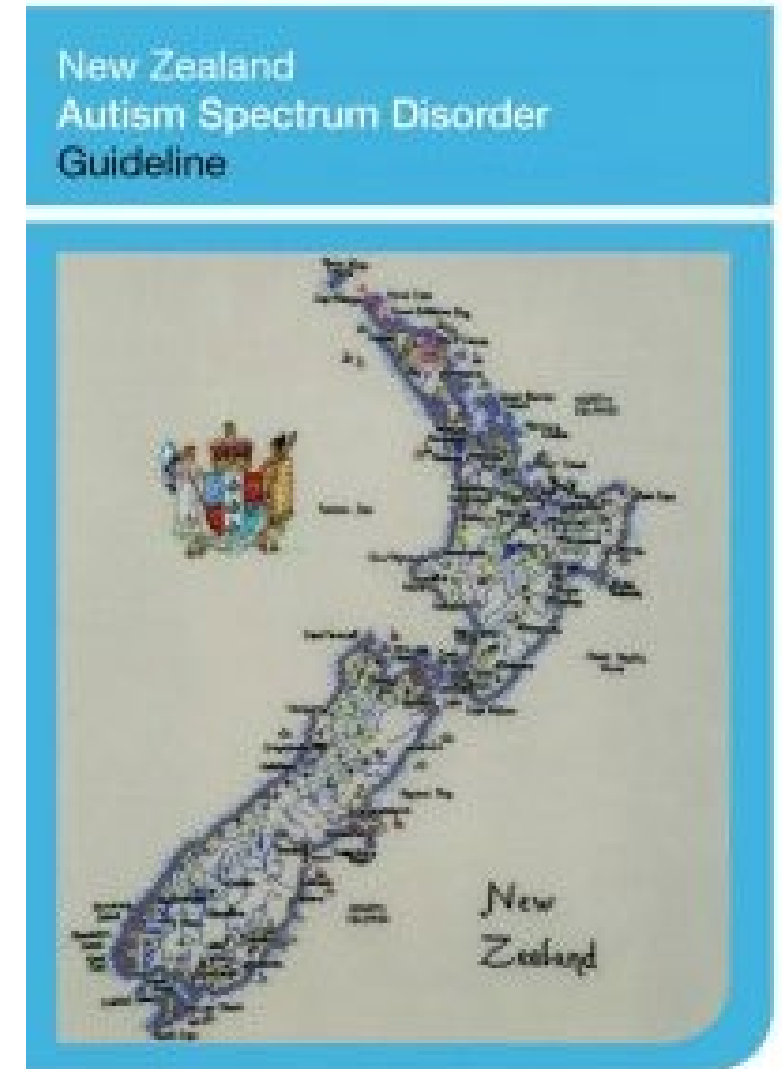
“The pathway to pursue a diagnosis is unclear and stressful”



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New Zealand Autism Spectrum Disorder Guideline

- Gap between recommendations made in the Guideline and work done to support actual implementation of the recommendations



What were our aims?



Understand:

- Autism/takiwātanga diagnostic processes
- Implementation of the NZ Guideline

To:

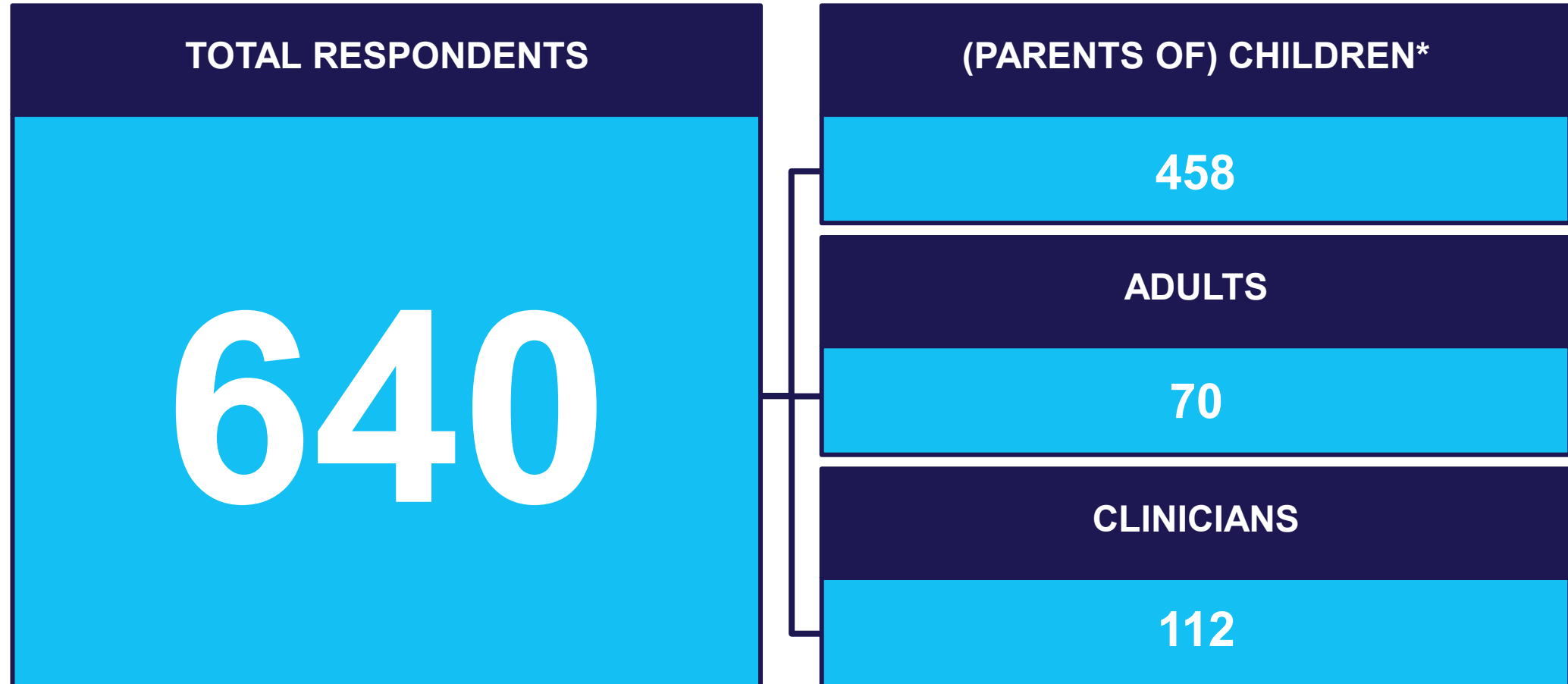
1. Provide actual data
2. Recommend improvements

Who did we ask?

1. Parents of children on the autism spectrum
2. Autistic adults
3. Clinicians



Who responded?



Three key phases



1. Identification and initial help



2. The diagnostic process



3. Post-diagnostic support

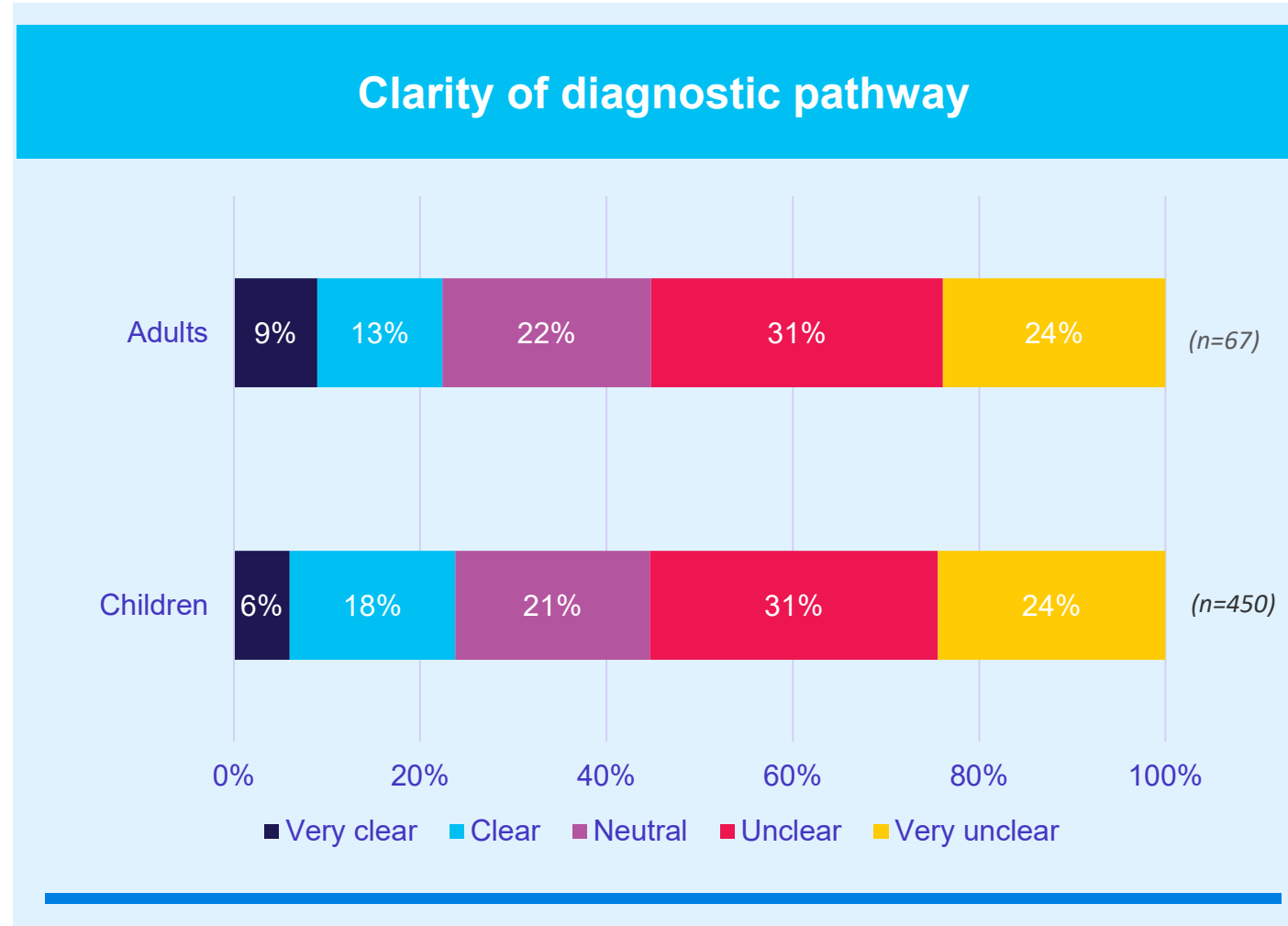
1. Identification and initial help



“[The] GP gave the “he’ll grow out of it” answer. I went back a week later not happy with that, and the next GP was incredible and put through an urgent referral.” - Parent

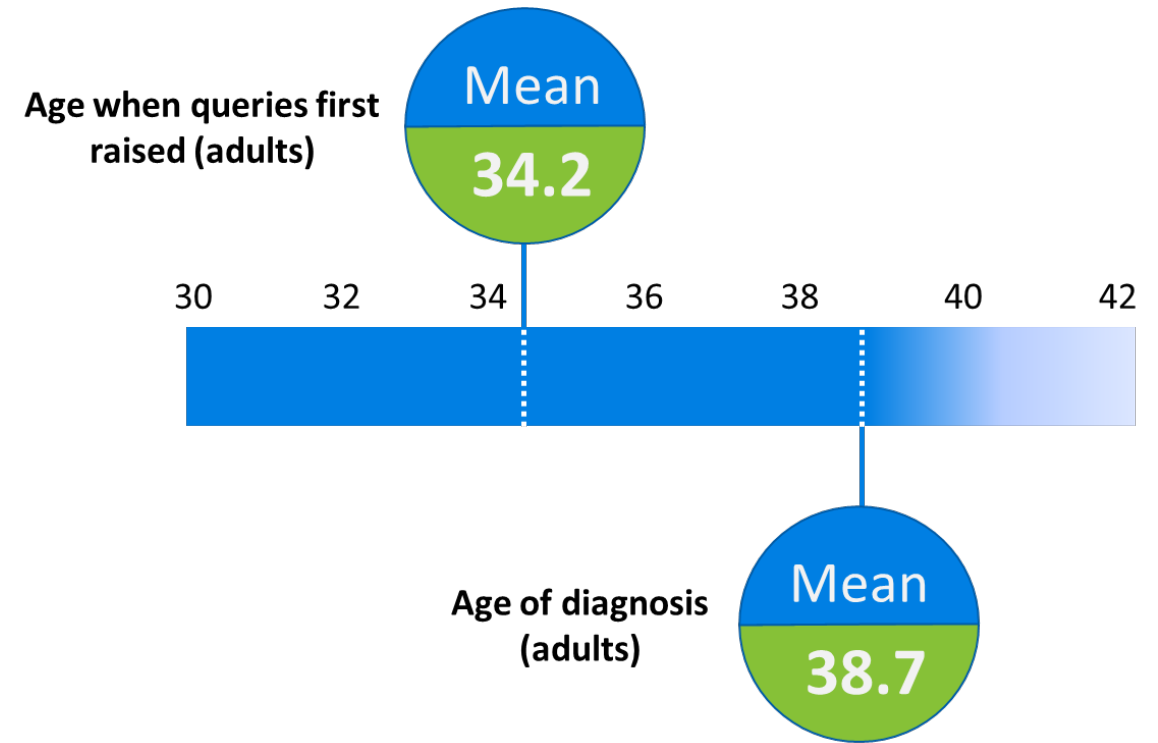
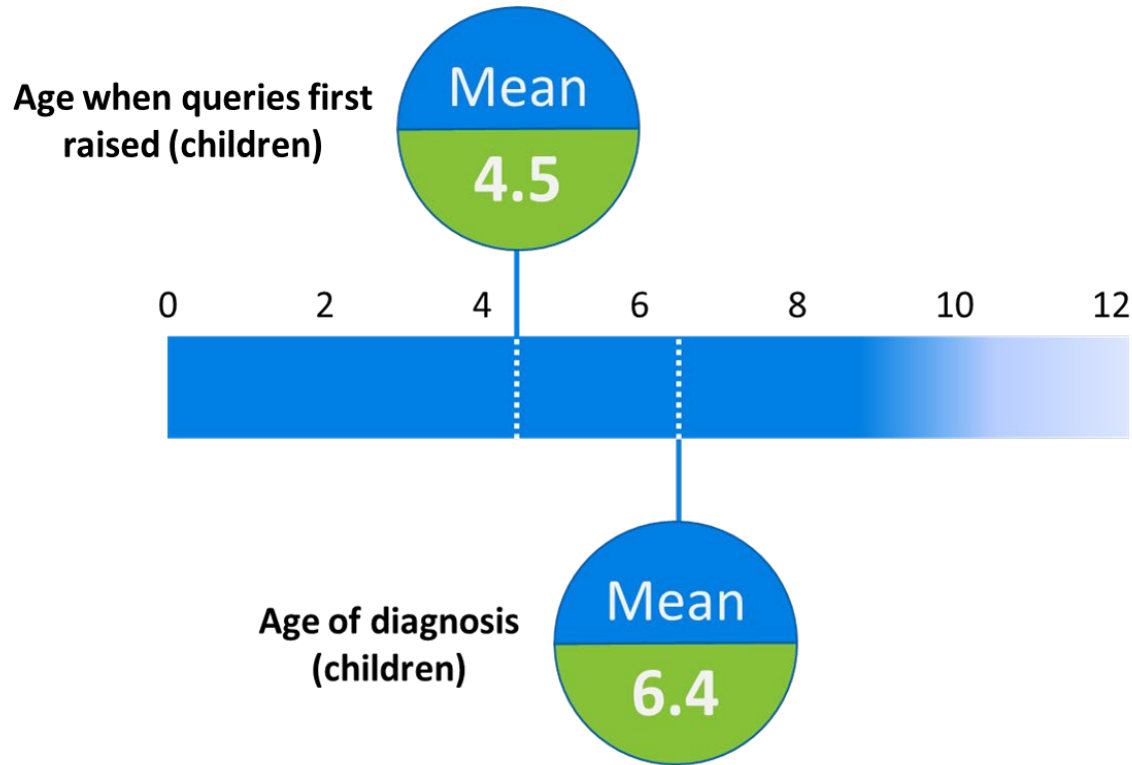
The diagnostic pathway is unclear

Less than one quarter said the pathway was clear.



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Getting a diagnosis takes a long time



2. The diagnostic process

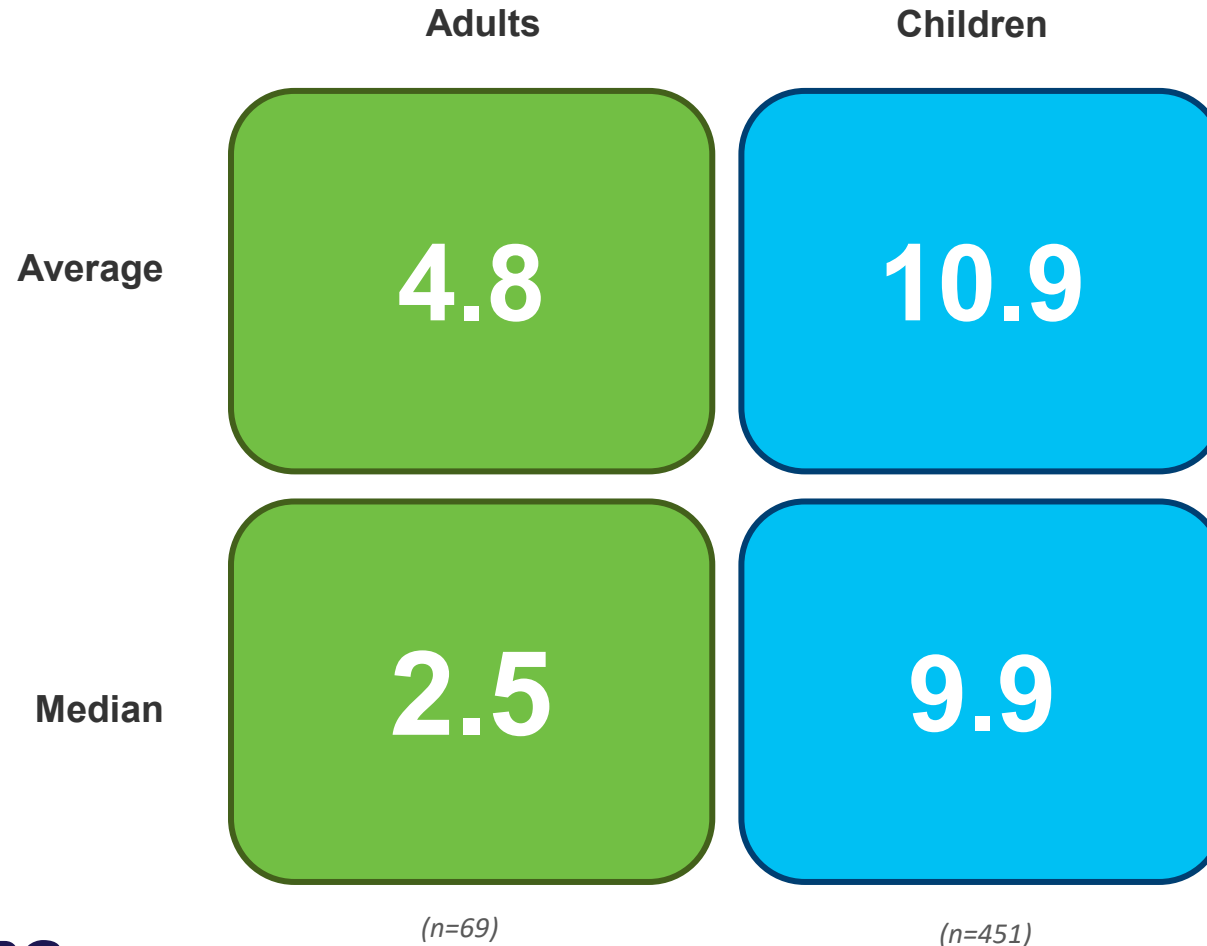


“I feel the process was long and stressful, especially as there was three years where we could have [had] a diagnosis and been receiving some support.” - Parent

“Very quick and easy as I went privately, but very expensive. I had heard that it was potentially very slow and quite traumatic to go through the public system and I didn’t want to make a difficult situation even more difficult for myself so I found the money to go privately.” - Adult

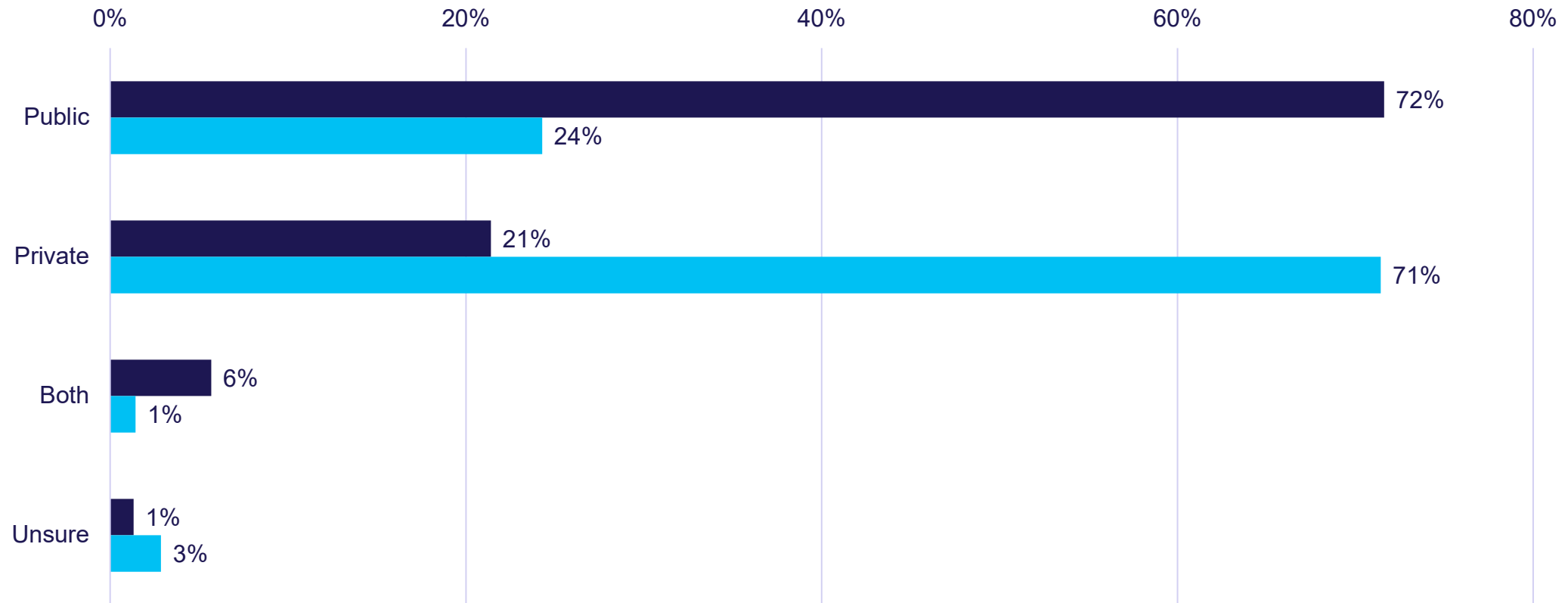
Children wait a long time for a diagnosis

Total wait times (months) to obtain a diagnosis for children and adults



Children went public, adults went private

Diagnostic setting for children and adults



Differences between public and private settings

Average number of clinicians who contributed to the assessment process for a diagnosis

*“Comprehensive [multidisciplinary] team assessments have very long waiting times (over a year in some places).”
- Clinician*



Some common positive experiences

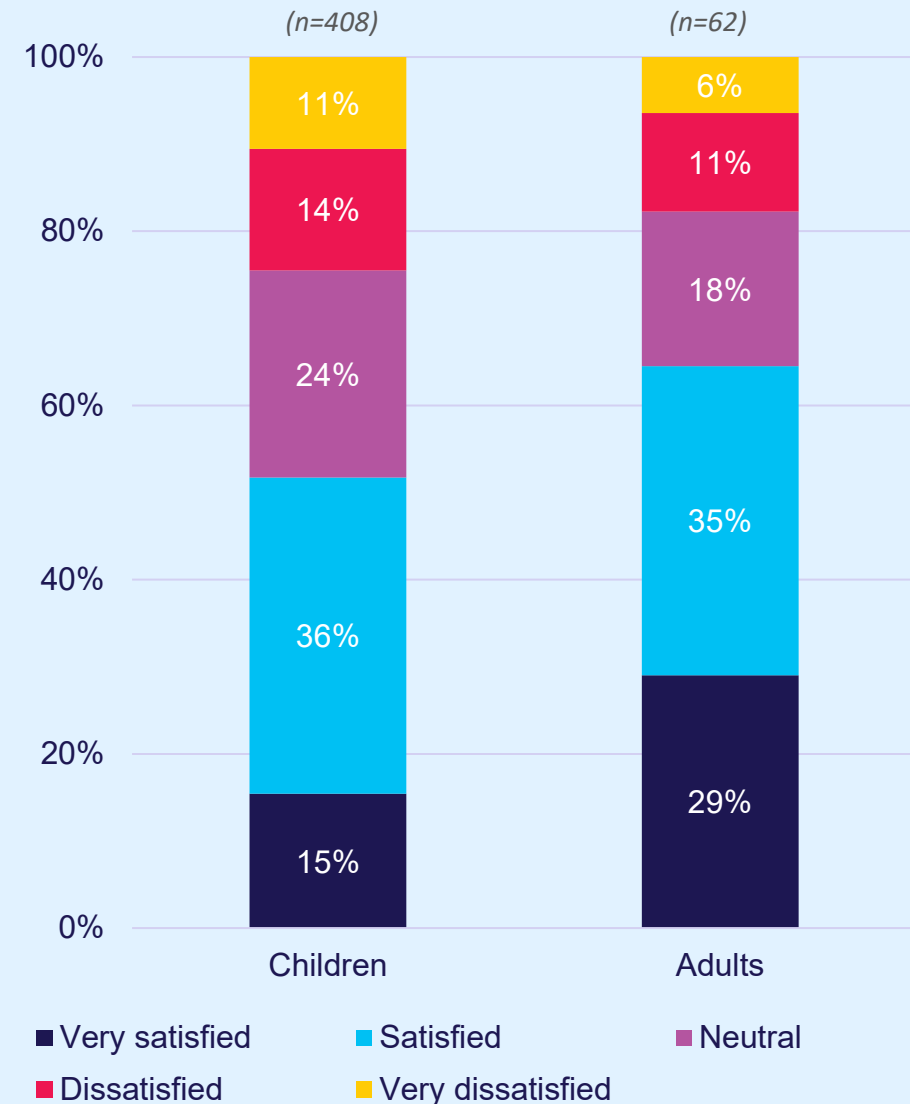
“I liked the multidisciplinary team who did the diagnosis. It was thorough.”
- Parent

“The Psychologist was excellent at talking me through each step. We took our time and I found that therapeutic.”
- Adult

Moderate overall satisfaction with the diagnostic process

“The actual process is fine, it’s just accessibility that makes it hard, we waited years to be seen.” - Parent

Overall satisfaction with the diagnostic process



3. Post-Diagnostic Support

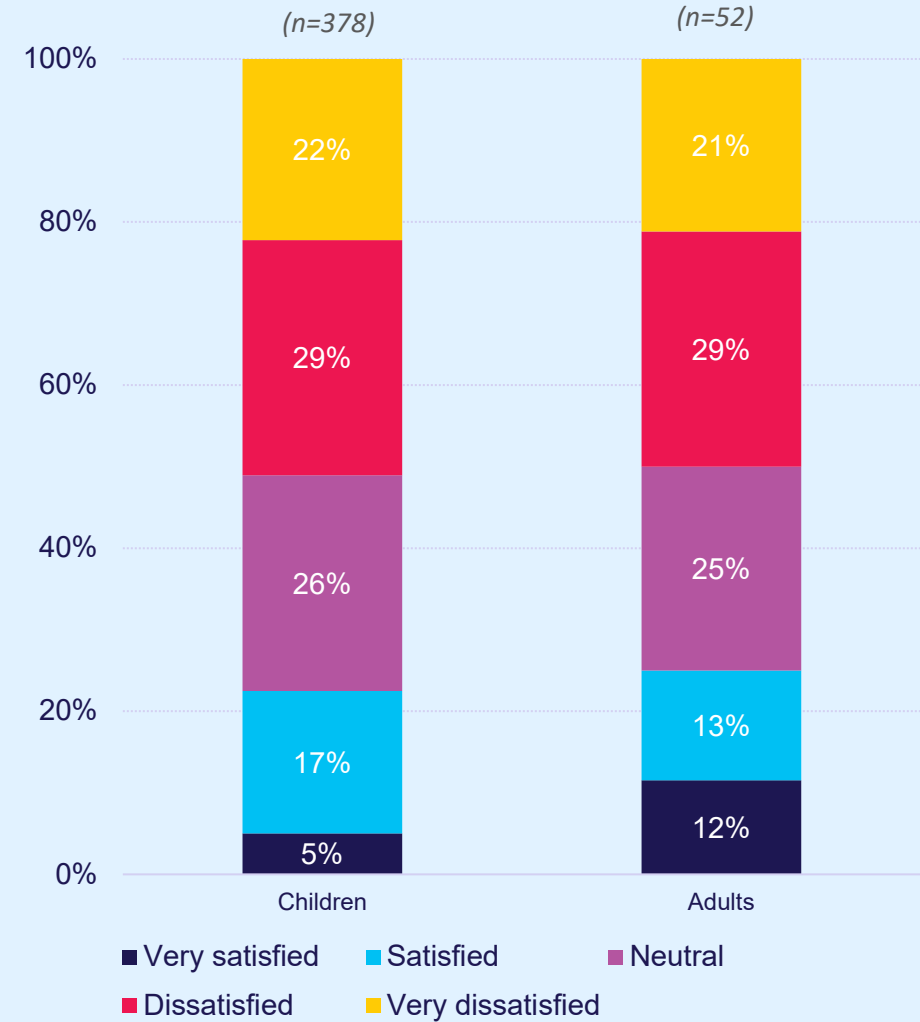


*“What support? There is /
was no support!” - Adult*

Poor satisfaction with post-diagnostic support

“I feel like there are so many different organisations involved with autism and it’s not so clear where they all fit, they seem to be doing their own thing.” - Parent

Overall satisfaction with post-diagnostic support



Dissatisfaction with post-diagnostic services and resources

- Specific support - i.e. counselling, vocational support
- Government funded support – i.e. Ministry of Education and Ministry of Health

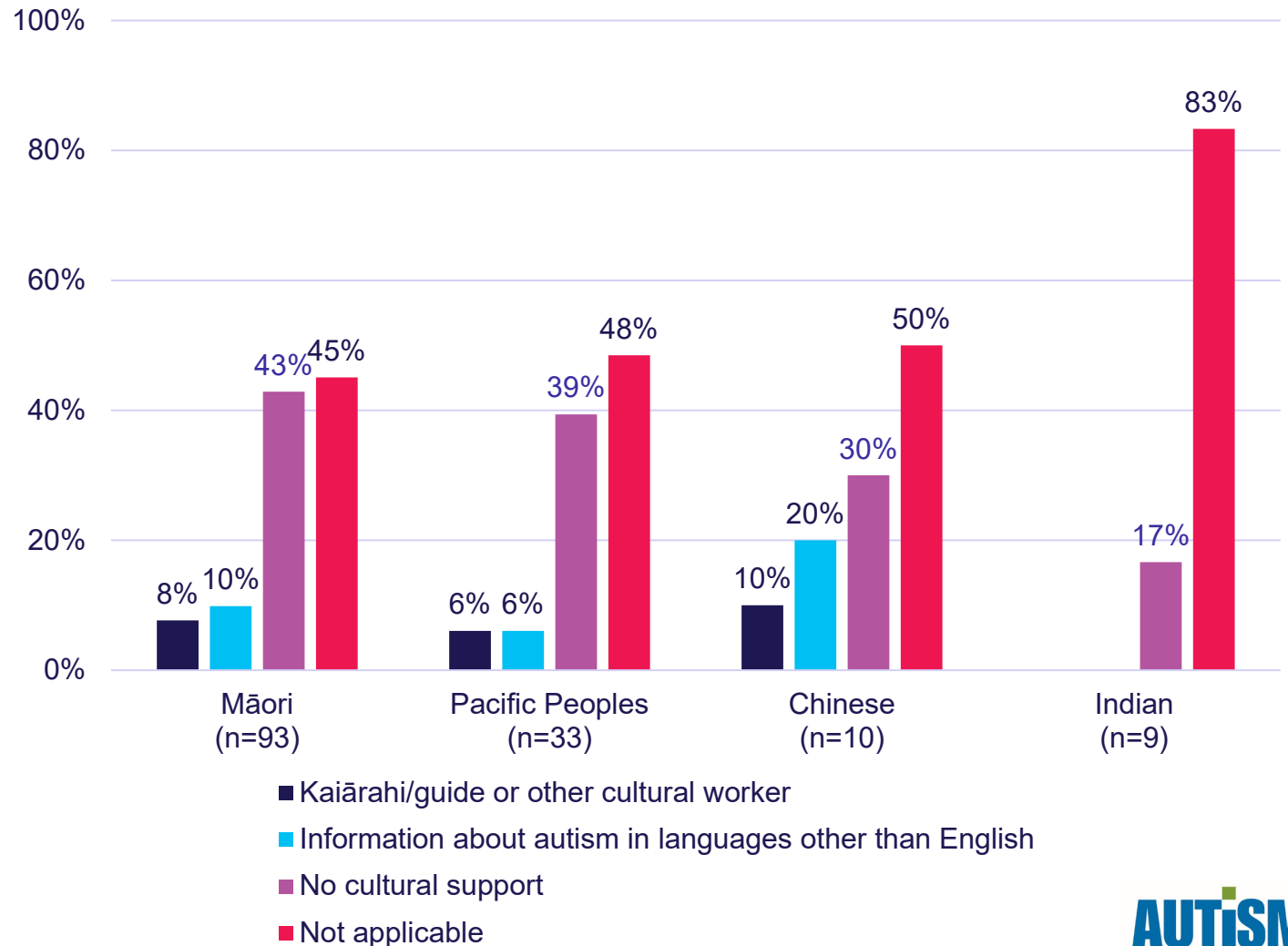
“I didn’t really understand the support I was given afterwards....

I wanted therapy, but they kept giving me people to take me shopping, but I’ve never really had too much trouble shopping.” - Adult

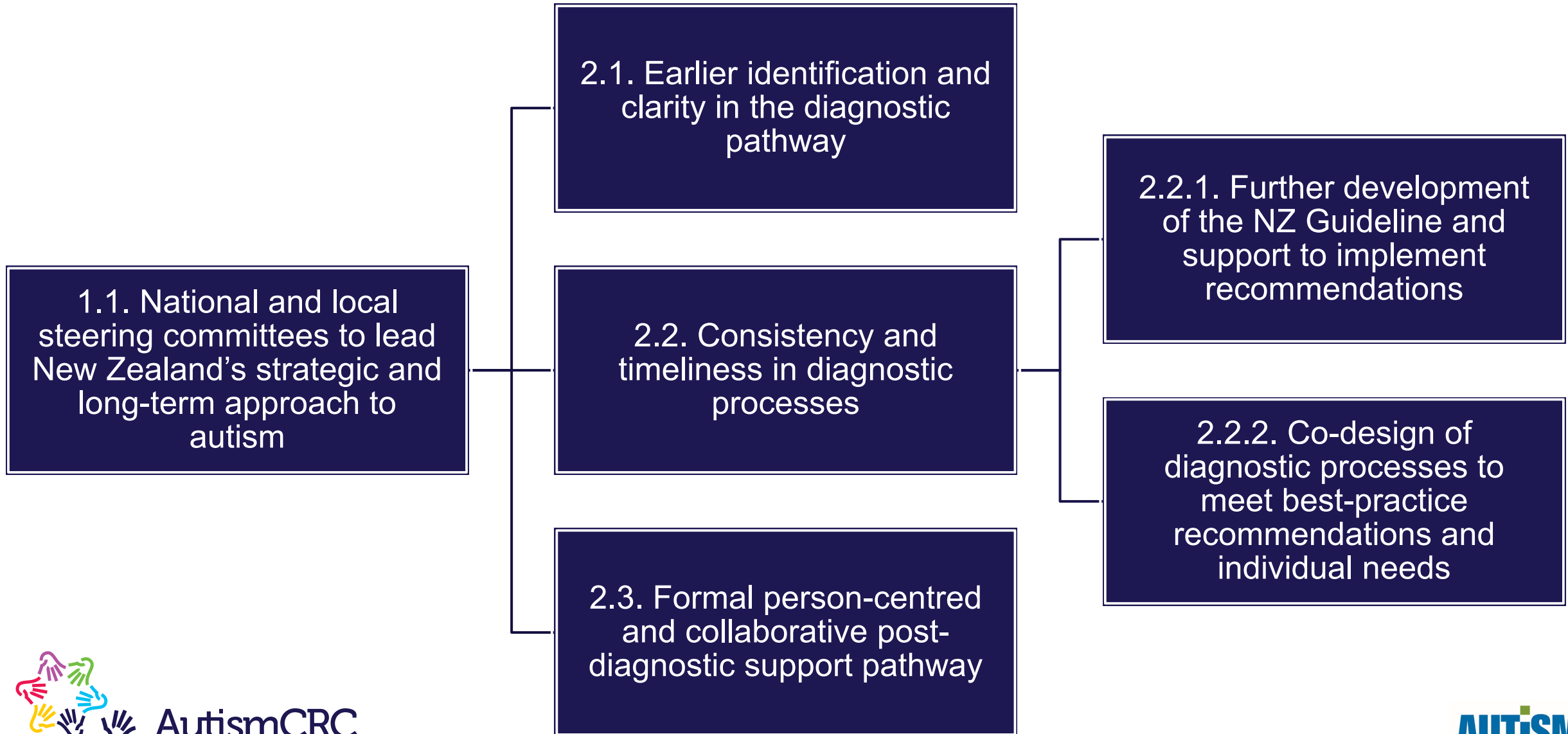
Not enough cultural support

"I have now done three assessments where the child's first language is Te Reo and interesting[ly] our families are not routinely asked if they would like a Te Reo interpreter in the same way as speakers of other languages might be asked."
- Clinician

Cultural support provided for children or their parents



Recommendations



Thank you

Questions?

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Autism CRC is the world's first national, cooperative research centre focused on autism. We are taking a whole-of-life approach to autism focusing on early years, school years and adulthood.