

Examining Language and Communication in Autistic People with Complex Needs – a Systematic Review of Procedural and Measurement Issues and Practice

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Background:

Approximately 50% of autistic individuals have intellectual disabilities and 30% remain minimally-verbal throughout life. This group is grossly under-represented in research due to methodological challenges and inconsistencies in definitions of intellectual disability and minimal verbal ability. We therefore know least about language and communication functioning in those who demonstrate the most significant difficulties in these areas. This systematic review analyses existing approaches to conducting research with this population in order to determine best practice and inform future directions.

Aims:

To review the literature on language and communication function in autistic individuals with complex needs to derive recommendations for best practice in including this population in future research. The following questions were addressed:

- 1) What strategies are used for engaging, recruiting and retaining autistic participants with limited speech and/or intellectual disability in research?
- 2) What tools have been used with this population to capture language and communication skills?
- 3) How are minimal language and intellectual disability defined and operationalised?

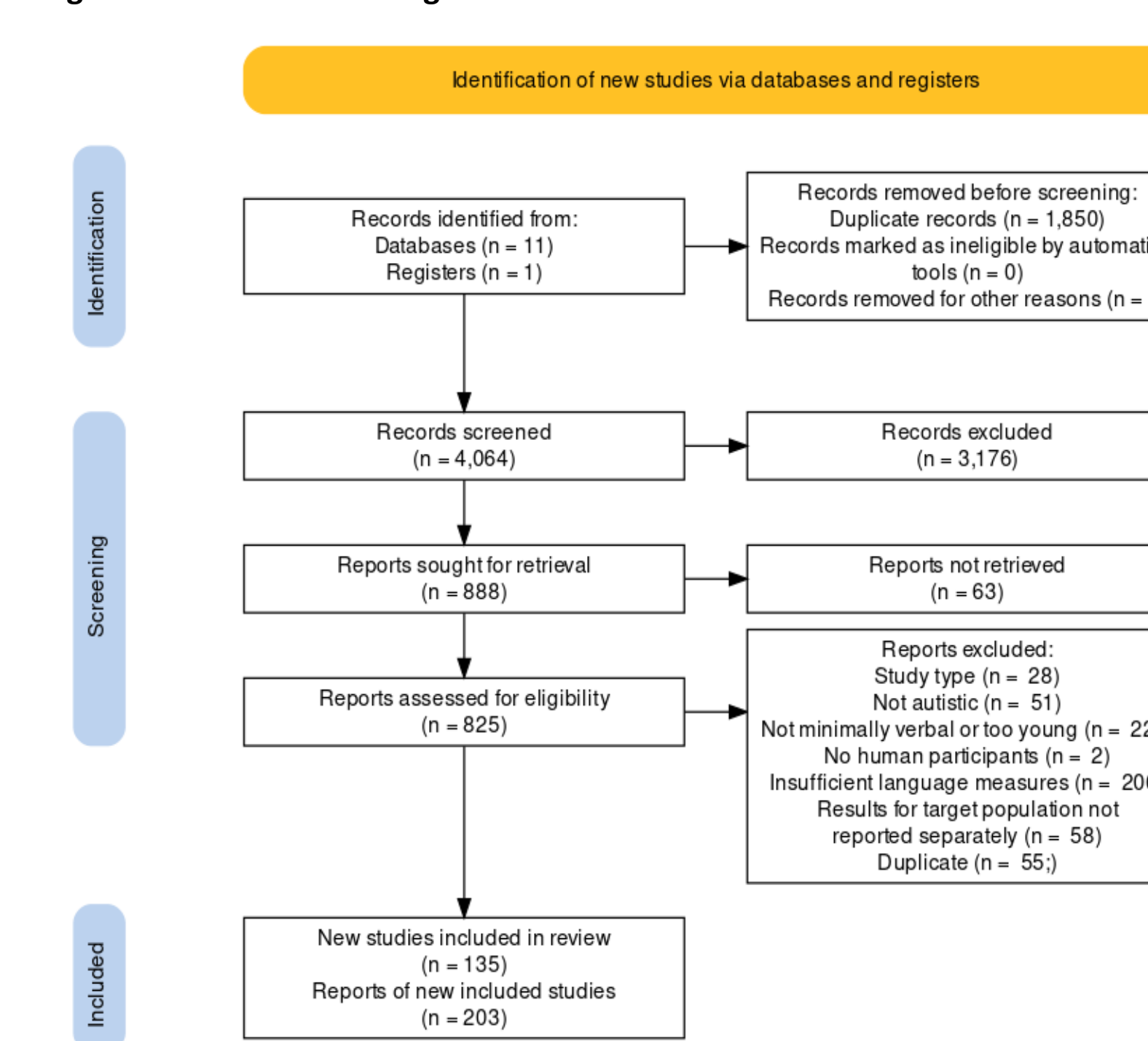
Methodology

- Systematic review of 12 databases using comprehensive range of search terms typically used to describe this population. (see Figure 1)
- Studies had to include participants with a diagnoses of ASD and describe participants using one of the search terms.
- Studies had to focus on and measure a language and/or communication outcome.
- PRISMA guidelines were followed.

Figure 1. Search Terms for systematic review

1	2	3
(autis* OR pervasive development* disorder* OR ASD OR PDD OR Kanner)	AND (learning disab* OR learning difficult* OR intellectual* impair* OR intellectual* disab* OR mental* disab* OR retard* OR minimally Verbal OR non-verbal OR Speech delay OR Language delay OR language impair*)	AND (social communication OR verbal behaviour OR Language Intervention OR Social skill OR social engagement OR Vocalis* OR response OR Language domain OR Oral language OR Eye contact OR Pointing OR Showing OR imitat* OR gesture OR interaction OR imitation OR interaction OR non-verbal communication OR interaction characteristics OR attention OR attend OR AAC OR alternative augmentative communication)

Figure 2. PRISMA Flow Diagram



Preliminary Results:

- Of 4064 studies, 203 met relevant inclusion criteria (see fig 2).
- There is variation in how terminology is operationalised within the literature (see fig 3). Terms like minimally verbal, non-verbal and non-speaking are most frequently defined according to the number of words a person uses.
- 76 different measurement tools or approaches were used to characterise or define study samples. 30 of these were only used once throughout the literature. Figure 4 shows frequencies of all approaches used three or more times as a function of terminology used to describe the sample.
- Language function was often assessed in non-standardised ways, very frequently by manipulating/scaffolding the child rather than adapting the measurement tool (see fig. 5)
- 35% of Studies did not report on how or where participants were recruited.

Figure 3. Breakdown of how different terms are operationalized as a function of how samples are defined

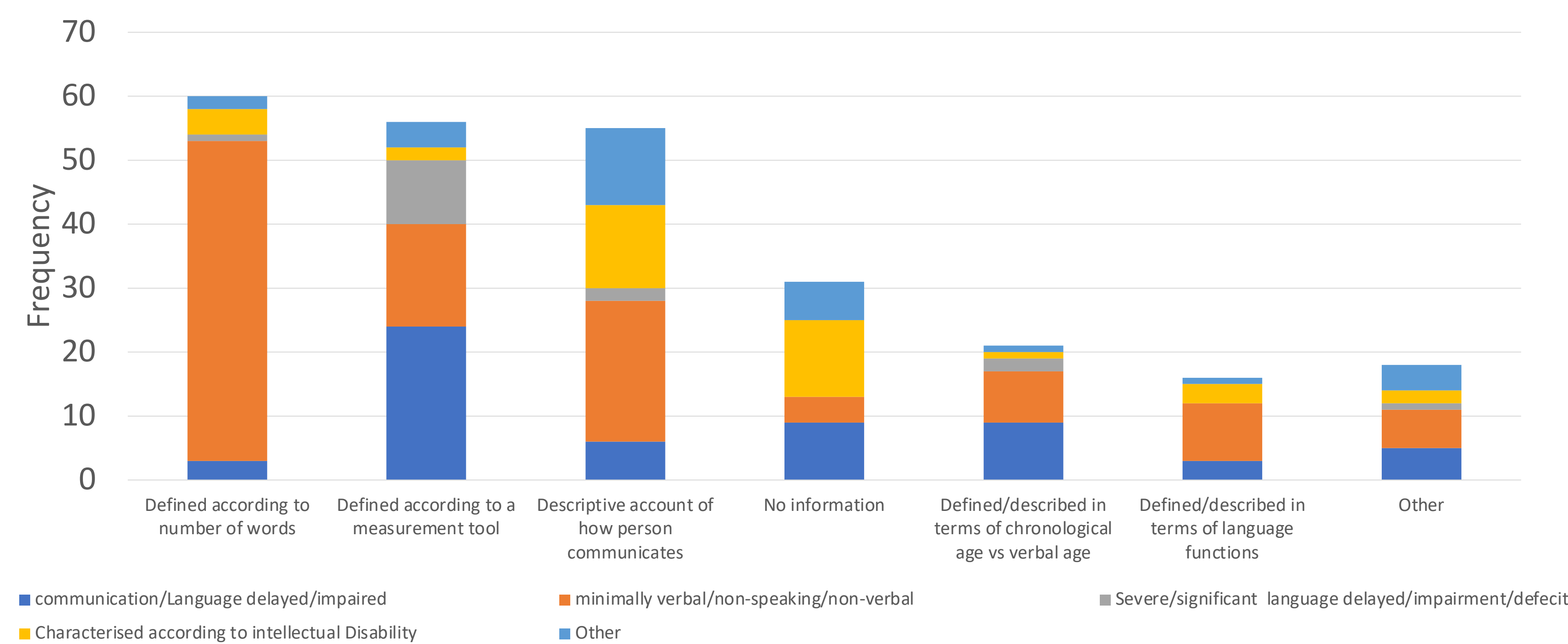


Figure 4. Breakdown of measurement approaches as a function of terminology used to describe sample

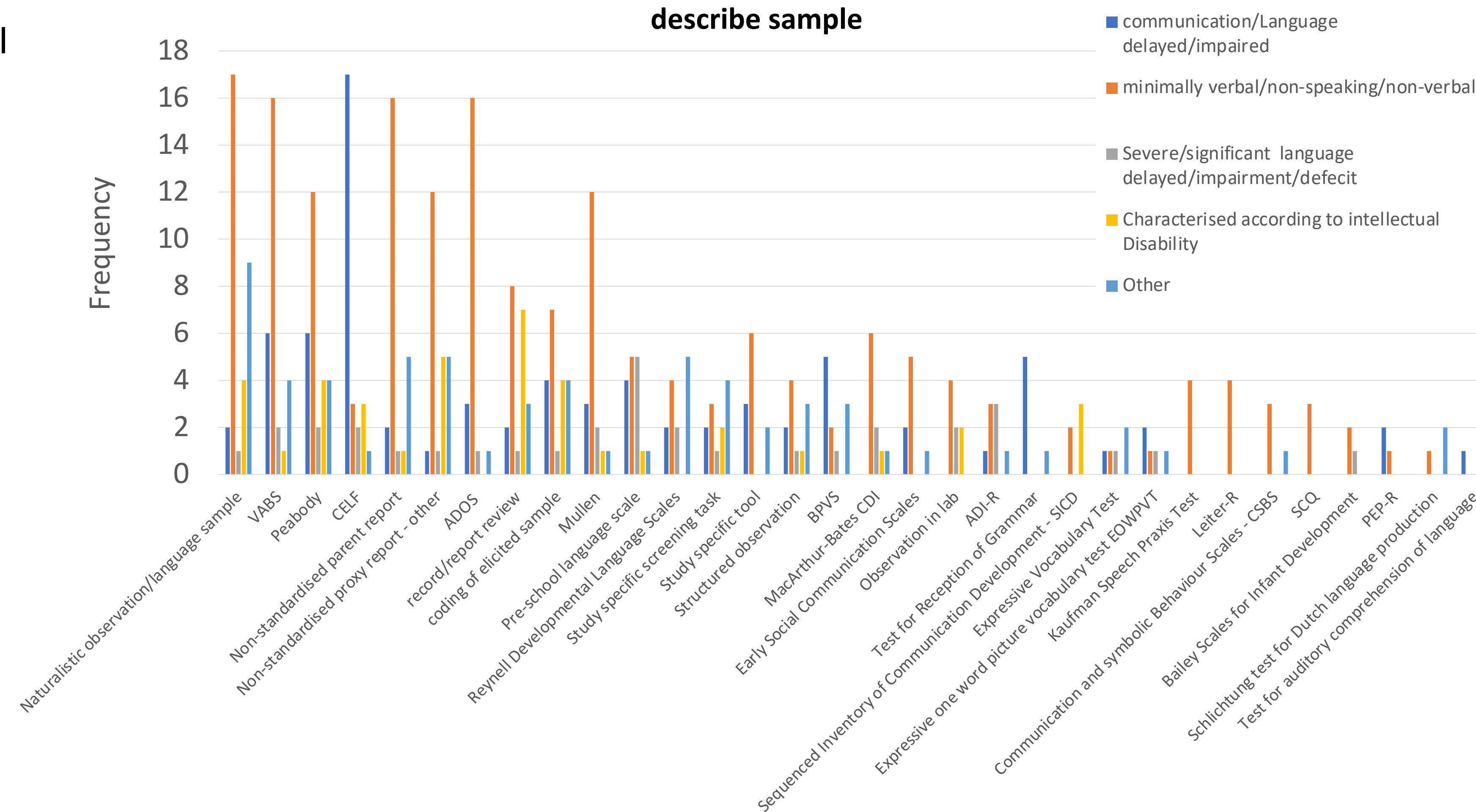
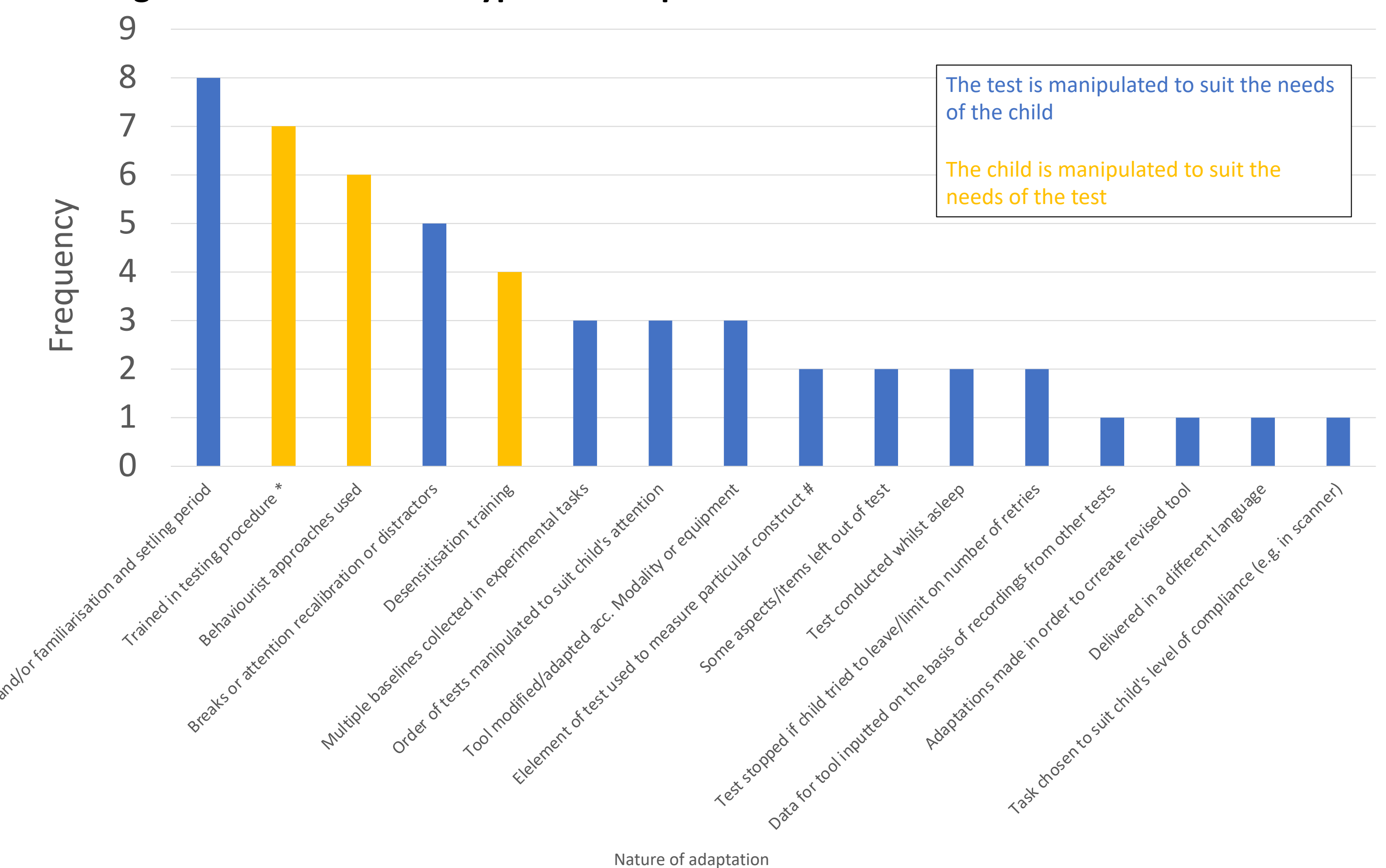


Figure 5. Breakdown of types of adaptations made to administration



Discussion:

- Despite attempts to highlight these issues in the existing literature, there remains little uniformity in approach to identifying, defining and operationalising language and communication for people who have complex support needs.
- Researchers predominantly rely on non-standardised approaches to measuring key indicators of language within this population.
- A significant proportion of researchers make adaptations to standardised tools in order to accommodate their participants needs. Further analysis of the data is needed to identify patterns in these adaptations. It is possible that this can inform development of more accessible standardized tools.
- The lack of reporting on methodological challenges such as recruiting and engaging participants makes it challenging to identify obstacles in this area or determine best practice.