

# Hearing Autistic Voices Through Inclusive Research Practices

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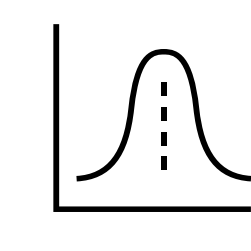
## The Goal

To develop a research methodology for interviewing autistic youth which enables meaningful participation by eliminating barriers.

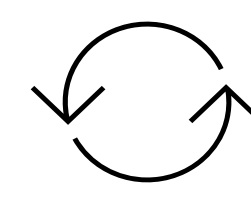
### Answer my research questions:

How do autistic students in NS describe their experience of school inclusion?  
What do they want their teachers to know?

## The Problem



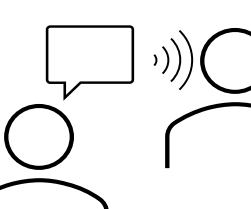
**Representative?** Research often excludes large portions of the autistic population, such as non-speaking people. (Courchesne et al., 2022; Milton, 2014; Nicholas et al., 2019; Roche et al., 2021)



**Replicable?** Many similar studies don't describe their methods fully, or at all. (Fayette & Bond, 2018; Jivraj et al., 2014; Tesfaye et al., 2019; Tyrrell & Woods, 2020)



**Ecologically Valid?** Few studies discuss having autistic people evaluate their design. (Fayette & Bond, 2017; Jivraj et al., 2014; Tesfaye et al., 2019; Tyrrell & Woods, 2020)



**Accurate?** Communication between autistic and non-autistic people is not always accurate. (Alkhalidi et al., 2019; Crompton et al., 2020; Milton, 2012, 2014)

## The Solution

**Universal Design:** Interview designed to accommodate a wide range of needs; all tools provided to all participants.

**Describe Methods:** Provide full protocol in published work.

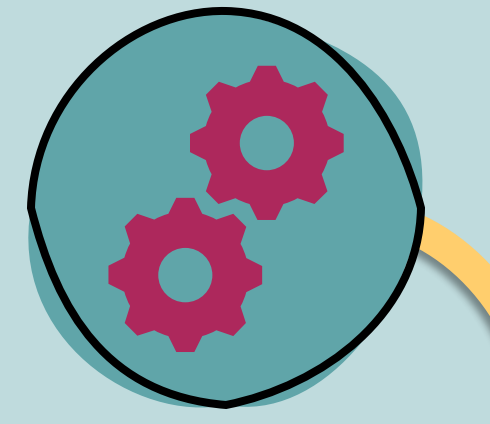
**Autistic Involvement:** Base protocol on those studies designed with autistic input. (Courchesne et al., 2022; Goodall, 2018, 2020)

**Autistic Researcher:** Facilitate accurate, autistic-to-autistic communication and promote feeling of safety. (Crompton et al., 2020; Milton, 2012, 2014)

## Support Considerations

### Processing

- Need for additional processing time
- Difficulty with open ended questions



### Communication

- Difficulty responding under pressure
- Need for different output modalities



### Anxiety

- Need for predictability
- Preference for structure



## Autistic-Approved Interview Materials

### Inclusive Practices

- Provide interview questions ahead of time.
  - Allows additional processing time, reduces anxiety.
- Honour and offer alternative communication.
  - Recruiting flyer indicates *all communication accepted*.
  - Interview materials allow alternatives to speech.
- Follow autistic communication norms.
  - Use concrete wording so questions non-ambiguous.
  - Provide sample responses; further reduce ambiguity.
- Use structured activities.
  - "Jump start" thought process to support wordfinding.

### Meeting Participants' Needs

These needs intertwine.  
Meeting one helps with others.

(Courchesne et al., 2022; Goodall, 2018, 2020)

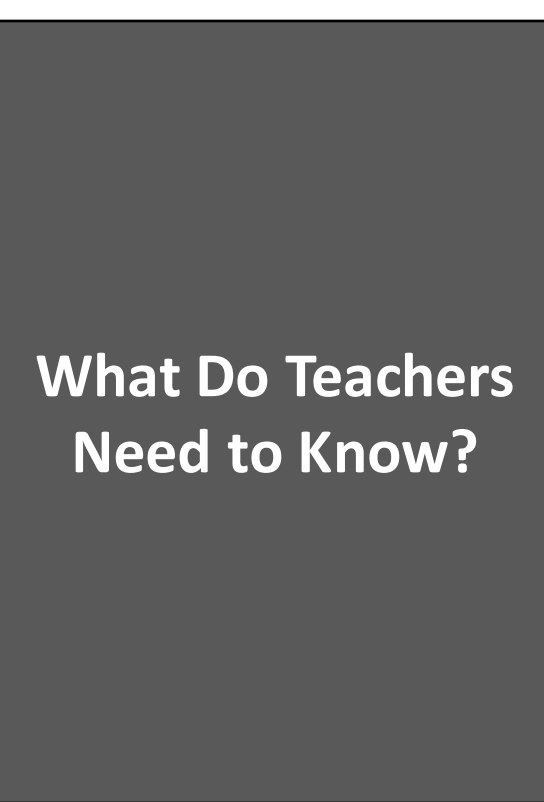
### Figure 1 Question Cards

(Courchesne et al., 2022)

At the beginning of the interview, the participant arranges the cards to determine the interview schedule.



- Provide structure
- Gives autonomy
- Create a visual schedule they can change and refer to as needed.

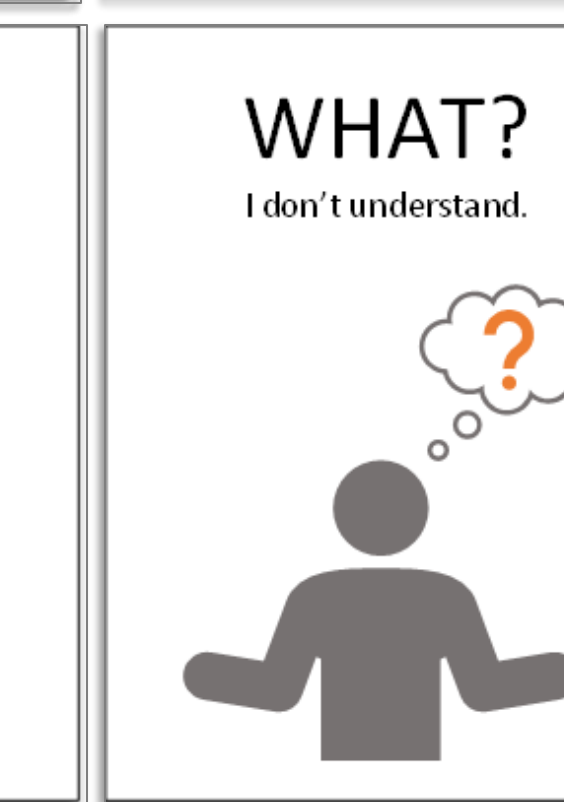
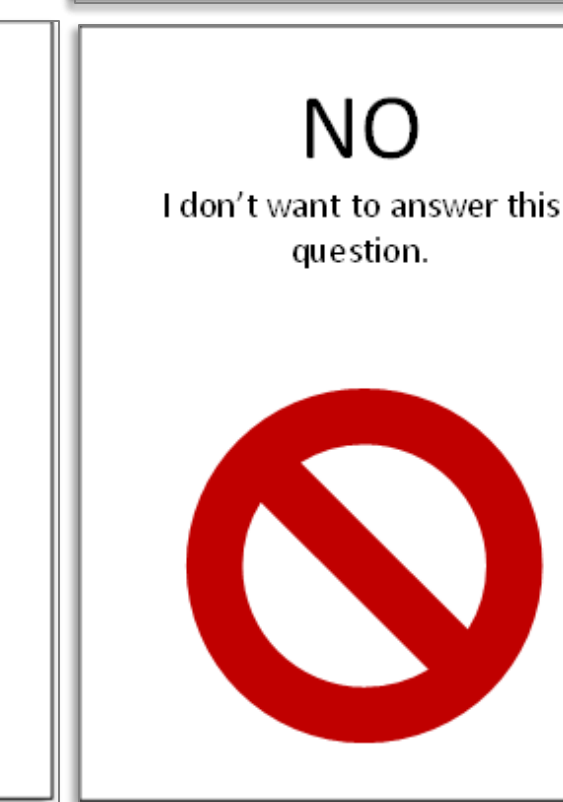
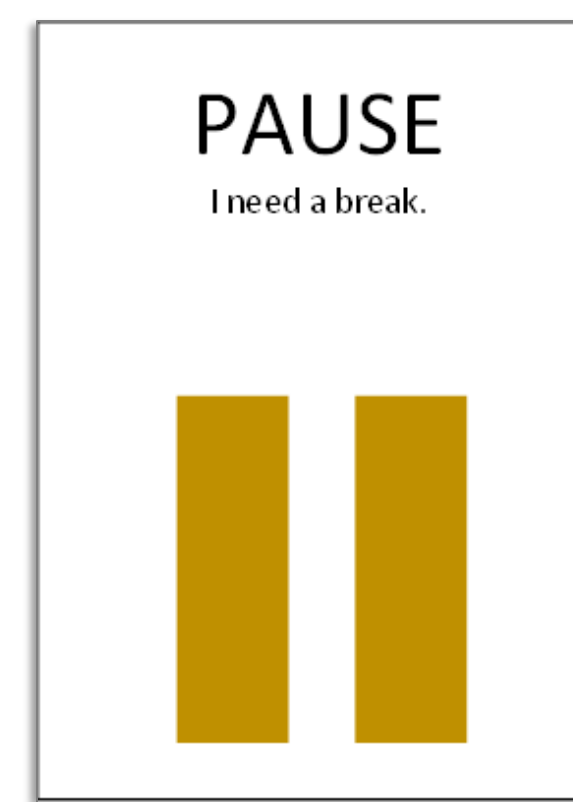
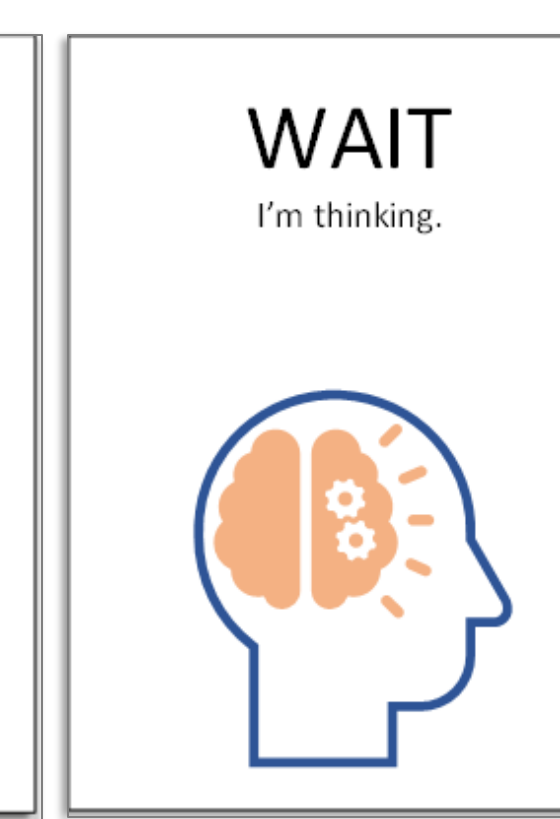
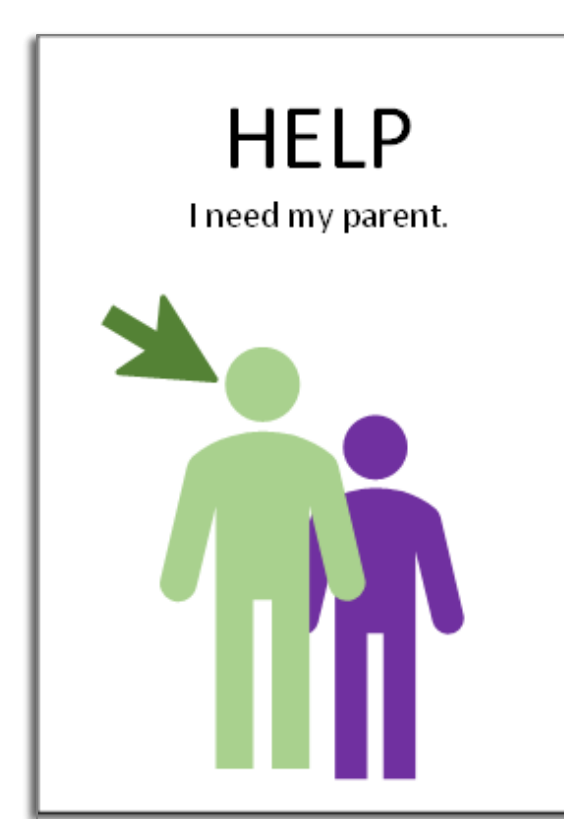


### Figure 2 Communication Cards

(Courchesne et al., 2022; Goodall, 2020)

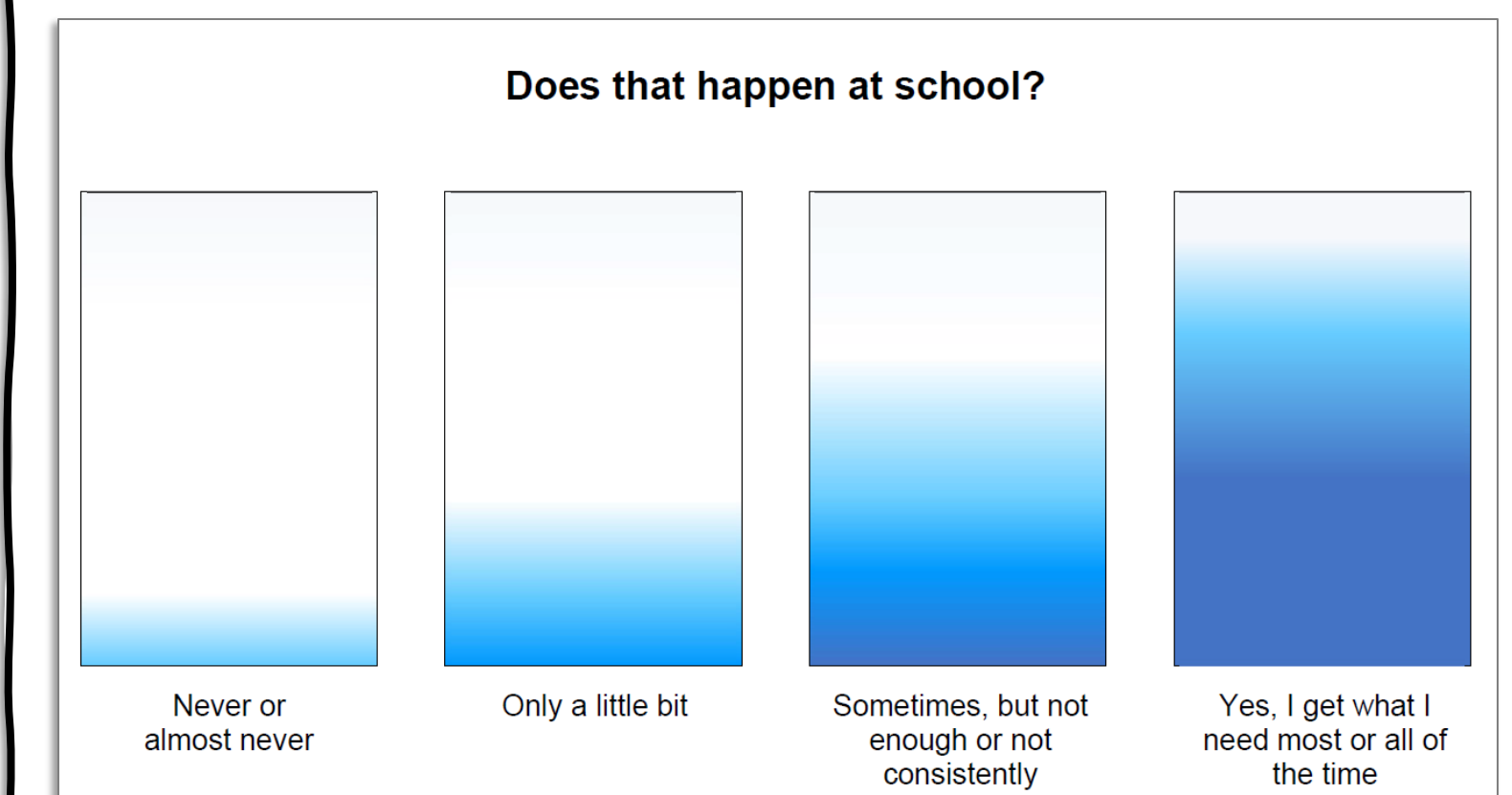
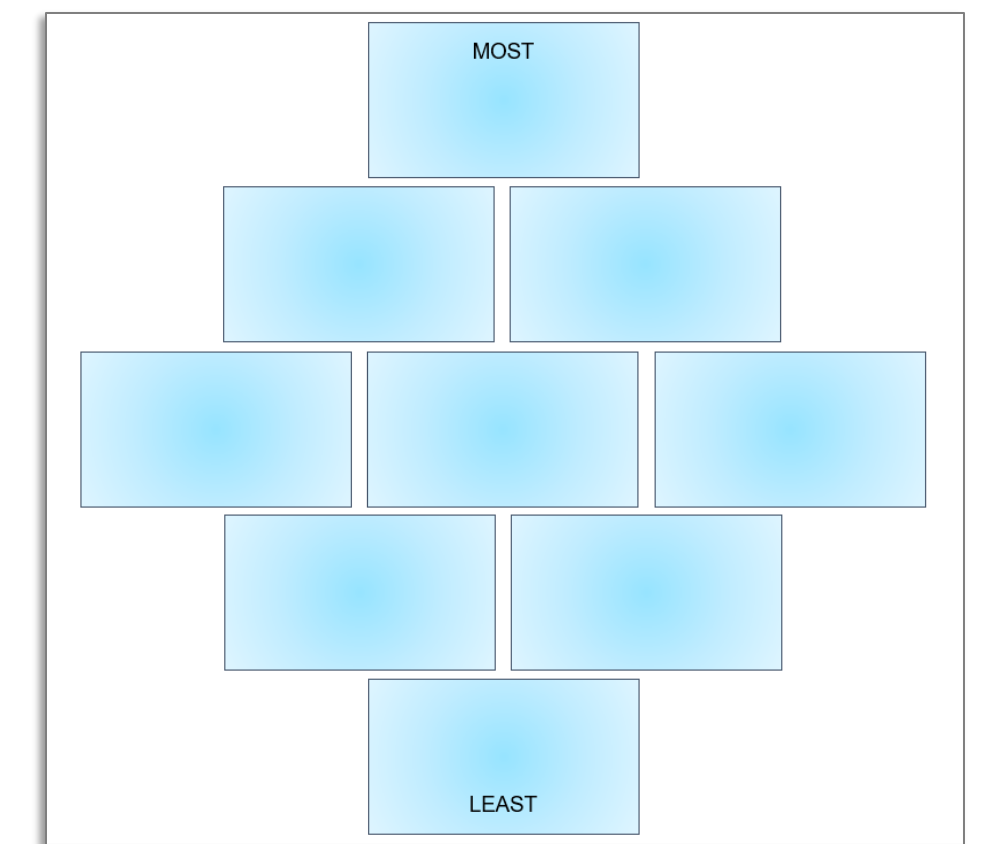
These cards support ongoing, meaningful engagement and provide an alternative way to communicate important needs. Some autistic people have intermittent speech abilities which may fluctuate with stress. (Zisk & Dalton, 2019)

- Provides a sense of safety
- Gives autonomy
- Reduce processing demands associated with language production; especially valuable during stressful moments.



### Figure 3 Visual Rating Scales

Adapted to support visual processing. Items are printed on cards; cards can be placed directly on the scale.



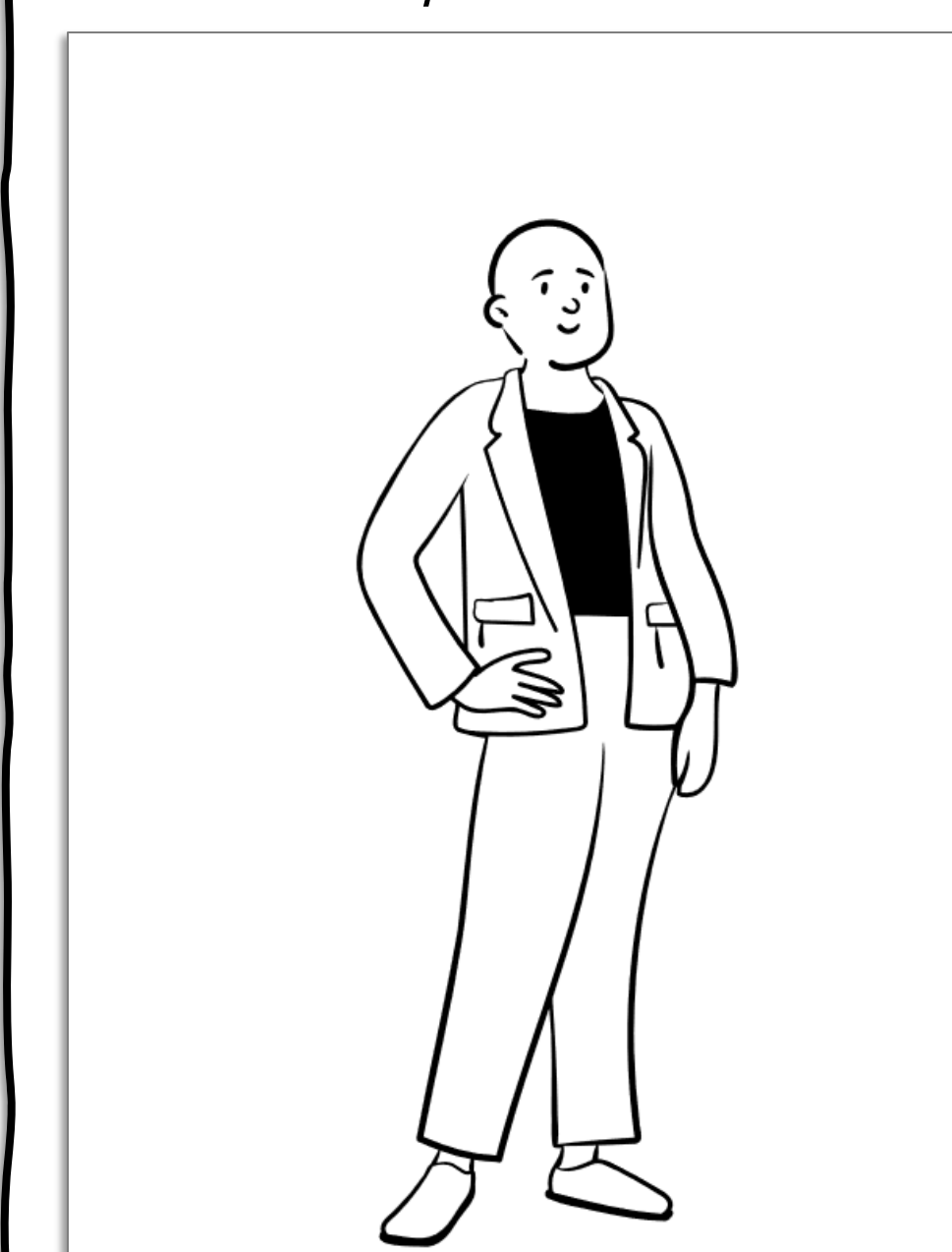
**3a.** Diamond Ranking  
Participants rank items from least to most important contributors to the experience or construct in question.

**3b.** Visual Likert Scale

### Figure 4 Alternative Activities

Providing options supports varying needs, preferences. (Courchesne et al., 2022)

**4a.** "Ideal Teacher." (Goodall, 2020)  
Participants can draw, write, or speak to answer: "What would you look for in a teacher for autistic students?"



**4b.** Examples of images used as visual prompts to answer: "What things are hard to cope with at school?"

## References

- Alkhalidi, R. S., Sheppard, E., & Mitchell, P. (2019). Is there a link between autistic people being perceived unfavorably and having a mind that is difficult to read? *Journal of Autism and Developmental Disorders*, 49(10), 3973–3982. <https://doi.org/10.1007/s10803-019-04101-1>
- Cashin, A., & Yorke, J. (2018). The relationship between anxiety, external structure, behavioral history and becoming locked into restricted and repetitive behaviors in autism spectrum disorder. *Issues in Mental Health Nursing*, 39(6), 533–537. <https://doi.org/10.1080/01612840.2017.1418035>
- Clark, M., & Adams, D. (2020). Parent perspectives of what helps and hinders their child on the autism spectrum to manage their anxiety. *Clinical Psychologist*, 24(3), 315–328. <https://doi.org/10.1111/cp.12222>
- Courchesne, V., Tesfaye, R., Miranda, P., Nicholas, D., Singh, I., Zwaigenbaum, L., & Elsabbagh, M. (2022). Autism Voices: A novel method to access first-person perspective of autistic youth. *Autism*, 26(5), 1123–1136. <https://doi.org/10.1177/13623631211042128>
- Crompton, C. J., Rogar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. *Autism*, 24(7), 1704–1712. <https://doi.org/10.1177/1362363120919286>
- Fayette, R., & Bond, C. (2018). A systematic literature review of qualitative research methods for eliciting the views of young people with ASD about their educational experiences. *European Journal of Special Needs Education*, 33(3), 349–365. <https://doi.org/10.1080/08856257.2017.1314111>
- Honeybourne, V. (2015). Listening to pupils. *Special Education Needs*, 74, 58–59.
- Jivraj, J., Sacrey, L.-A., Newton, A., Nicholas, D., & Zwaigenbaum, L. (2014). Assessing the influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review. *Autism*, 18(7), 782–793. <https://doi.org/10.1177/1362363114539858>
- Mauthner, M. (1997). Methodological aspects of collecting data from children: Lessons from three research projects. *Children & Society*, 11(1), 19–28. <https://doi.org/10.1111/j.1099-5861.1997.tb00003.x>
- Mayes, S. D., & Calhoun, S. L. (2007). Learning, attention, writing, and processing speed in typical children and children with ADHD, autism, anxiety, depression, and oppositional-defiant disorder. *Child Neuropsychology*, 13(6), 469–493. <https://doi.org/10.1080/09297040601112773>
- Milton, D. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*, 27(6), 883–887. <https://doi.org/10.1080/09687599.2012.710008>
- Milton, D. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, 18(7), 794–802. <https://doi.org/10.1177/1362363114525281>
- Nicholas, D. B., Orjasjaeter, J. D., & Zwaigenbaum, L. (2019). Considering methodological accommodation to the diversity of ASD: A realist synthesis review of data collection methods for examining first-person experiences. *Review Journal of Autism and Developmental Disorders*, 6(2), 216–232. <https://doi.org/10.1007/s40489-019-00164-z>
- Roche, L., Adams, D., & Clark, M. (2023). Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism*, 25(2), 336–348. <https://doi.org/10.1177/136236312210967790>
- Tesfaye, R., Courchesne, V., Yusuf, A., Savion-Lemieux, T., Singh, I., Shikalo-Thomas, K., Miranda, P., Widdell, C., Smith, I. M., Nicholas, D., Sattmar, P., Bennett, T., Duku, E., Georgiades, S., Kems, C., Vaillancourt, T., Zaidman-Zait, A., Zwaigenbaum, L., & Elsabbagh, M. (2019). Assuming ability of youth with autism: Synthesis of methods capturing the first-person perspectives of children and youth with disabilities. *Autism*, 23(8), 1882–1896. <https://doi.org/10.1177/1362363119831487>
- Thurman, M. P. (2016). First person perceptions on intelligence, cognition, and sensory processing in autism (Ph.D., University of Northern Colorado). In *ProQuest Dissertations and Theses*. <https://www.proquest.com/docview/136841427/abstract/686550288244AF3PQ/1>
- Tyrrell, B., & Woods, K. (2020). Gathering the views of children and young people with ASD: A systematic literature review. *British Journal of Special Education*, 47(3), 376–398. <https://doi.org/10.1111/1467-8578.12311>
- Zisk, A. H., & Dalton, E. (2019). Augmentative and alternative communication for speaking autistic adults: Overview and recommendations. *Autism in Adulthood*, 1(2), 93–100. <https://doi.org/10.1089/aut.2018.0007>