THE VIEWS OF AUTISTIC ADULTS ON EARLY AUTISM INTERVENTIONS: A SYSTEMATIC LITERATURE REVIEW

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(Kathy Leadbitter, Neil Humphrey, Alex Sturrock)

INTRODUCTION

❖ Early support for young autistic children, specifically educational or psychosocial.

❖ Autistic adults as stakeholders (social validity, social model of disability, neurodiversity movement)

❖ Heated topic in autism community

❖ Little research -> Systematic literature review

Leadbitter et al, 2021. Autistic self-advocacy and the neurodiversity movement: implications for autism early intervention research and practice

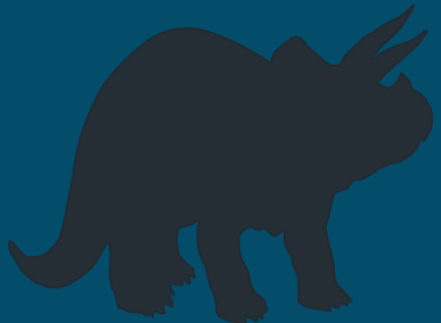Early interventions are extremely variable in their outcomes, methods and contexts. Even specific interventions within one approach can vary drastically.

We need to know more about **specific things** that are helpful or harmful so that:

- We considered it when designing new interventions;

- We could understand what happens as interventions change

- Parents and carers could make an informed choice.

13 papers
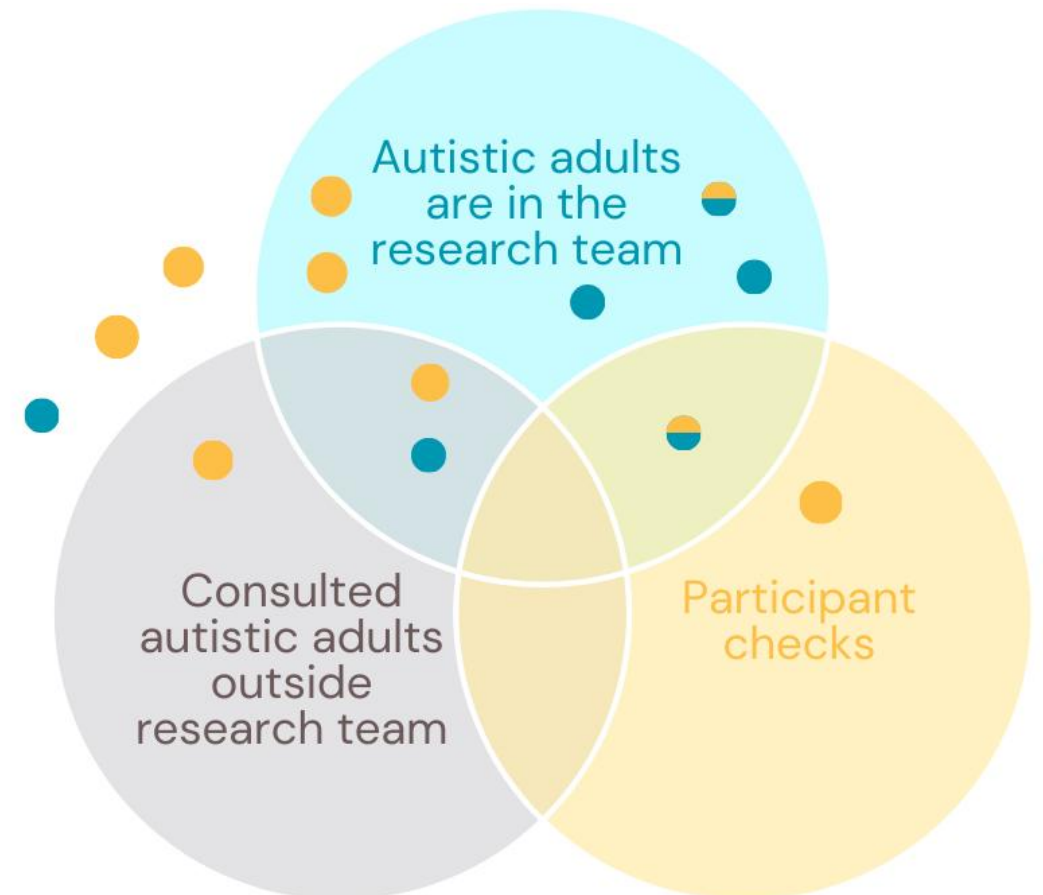
Focused on:
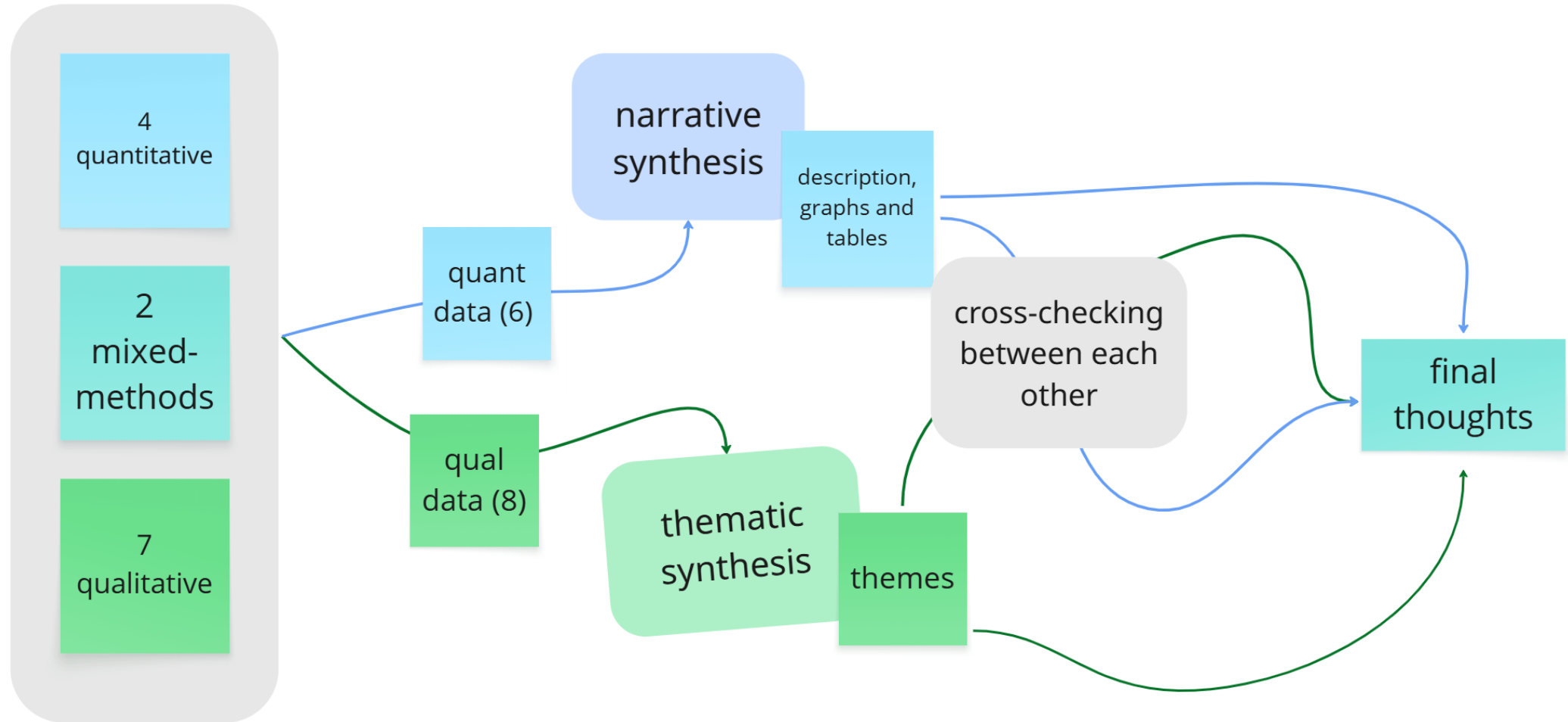early interventions in general (4)
ABA/behavioural (6)
other specific interventions (3)

4 studies on experiences, all qualitative, 3 of them on ABA

Countries: USA (7), Australia, UK, New Zealand, France

SYNTHESIS

QUALITATIVE THEMES

Respect our voice	**Accept our disability**
❖ Hear the child ❖ See the child	❖ Celebrate autistic lives ❖ Understand autistic challenges

Damage Done
(Previous experiences of autistic adults)

RESPECT OUR VOICE

HEAR THE CHILD

- Self-advocacy
- Assent
- Bodily autonomy
- Child-led

SEE THE CHILD

- Developmentally appropriate
- Play-based
- Positive affect
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"I expect this specific intervention to be good for some and bad for others, so consent is really important." (Schuck et al., 2023 , p.431)

"Have it be geared towards what the child is interested in and doing everything possible to make the child feel comfortable and welcomed in their learning environment. Which any other student would expect, right?" (Anderson, 2023)

DAMAGE DONE #1

- HARM. ABUSE AND HUMILIATION
- MINDLESS COMPLIANCE
- LONG-TERM NEGATIVE CONSEQUENCES

They taught me that adults get to do whatever they want with me. That others get to decide what is right or wrong for me. That I don't matter. (Cummings et al., 2020)

They physically made me sit the way they demanded without caring that it hurt. Once I was tied up for rocking (McGill & Robinson, 2021)

"... mindless compliance <...> is dangerous, absolutely dangerous because then if someone in power wants to do bad stuff to you, you don't know how to say no and I've actually got into some situations where maybe I wouldn't have if I'd known how to say no." (Cummings et al., 2020)

ACCEPT OUR DISABILITY

CELEBRATE AUTISTIC LIVES

- Autism acceptance
- Autism-affirming goals
- Strengths-based interventions
- Involving autistic adults

UNDERSTAND AUTISTIC CHALLENGES

- Changing environment- (e.g. sensory)
- Reducing demands (e.g. demands of a daily life)
- Embracing multiple means of communication

No autistic person should be taught to hide their autistic traits (Chazin et al., 2023)

"If an Autistic child or adult is distressed and not complying, that's indicating something is wrong with the environment or the demand, NOT the Autistic person". (Sterman et al., 2023)

DAMAGE DONE #2

"I was hyperattentive to adults, still can't imitate, and am unable to comply with expectations because I have sensory and movement control issues that aren't helped with drills and rewards. They are neurological problems, not problems with my social understanding or intellect."
(Anderson, 2023)

I was taught that being able to fool people I was neurotypical was my best goal in life (McGill & Robinson, 2021)

QUANTITATIVE FINDINGS

6 papers, 4 put into graphs, others analysed descriptively.

One paper (Turgeon & Lanovaz, 2020) performed a quantitative content analysis on the forum comments, five other studies used surveys.

	Goals	Methods	Setting, context	Intervention type
Chazin et al., 2024	Yes	Yes	Yes	General
Sulek et al., 2024	Yes			General
Waddington et al., 2023	Yes			General
Walton et al., 2023	Mention		Mention	General
Turgeon & Lanovaz, 2021				Behavioural
Baiden et al., 2024	Yes	Yes	Yes	Behavioural

GOALS – THE TABLE
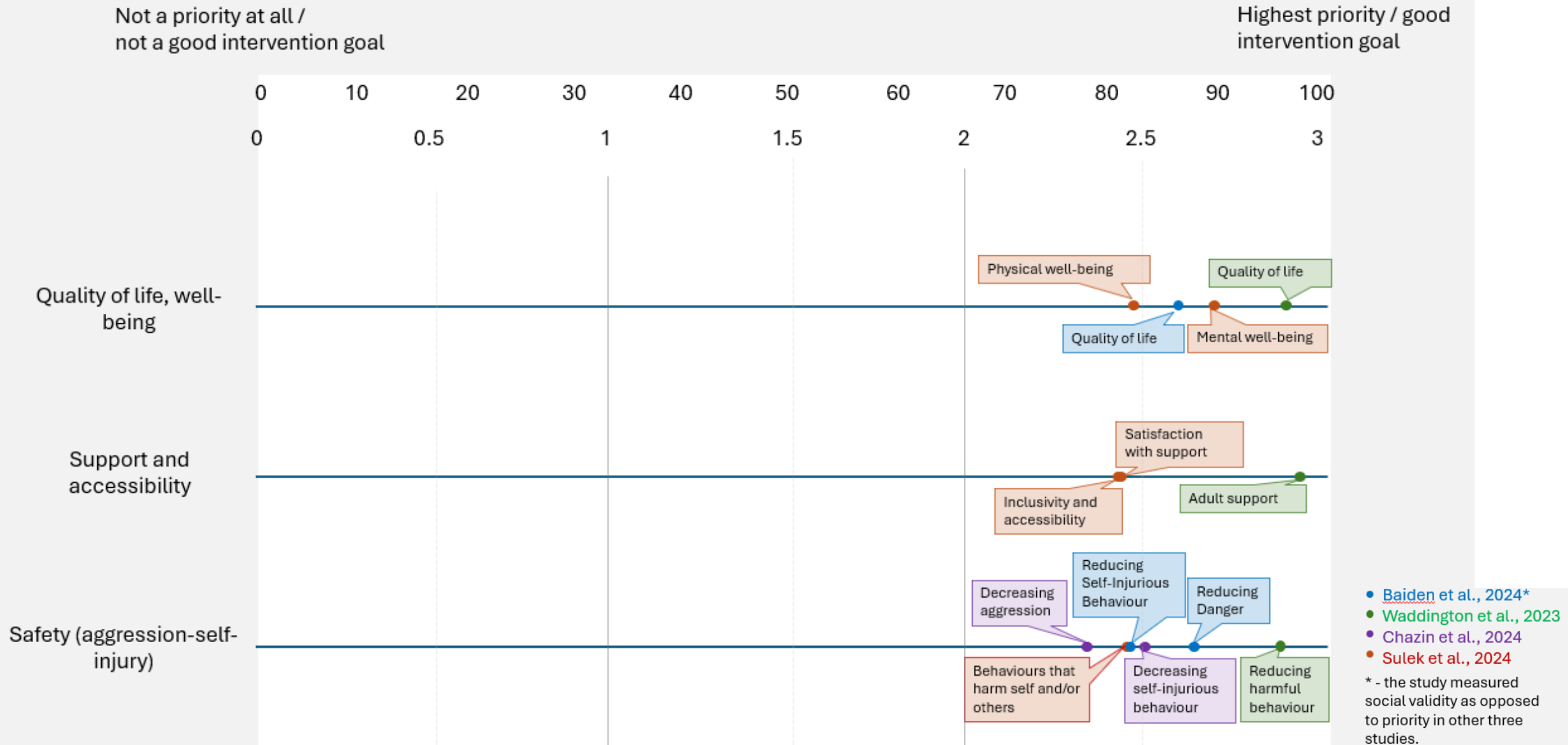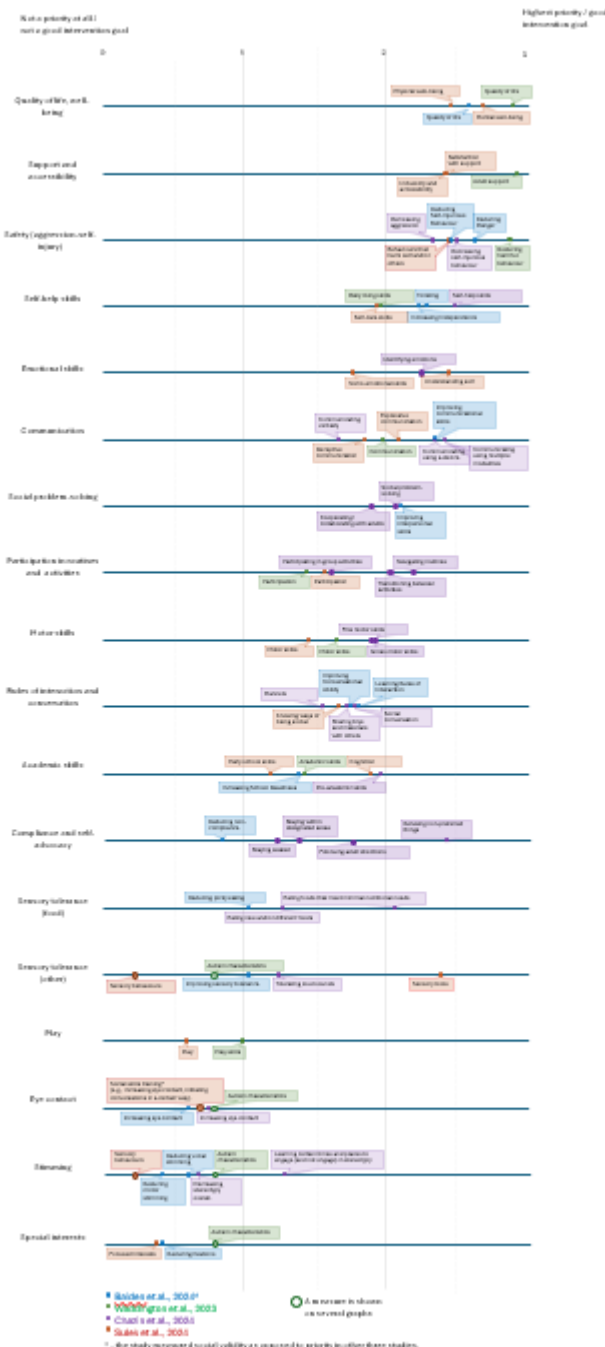
Highest: Quality of life/well-being, support and accessibility, safety.
Slightly below: self-help, emotional skills, communication, social problem-solving

Middle: participation in routine and activities, motor skills, rules of interaction and conversation, academic skills, [compliance/following directions]

Low: Sensory tolerance (food and otherwise), play, eye contact, reducing stimming, reducing special interests.

Autistic people from different samples and countries consistently position their priorities similarly

When parents and practitioners are asked, the difference is typically within 1 item (e.g. Strongly agree to agree)

DISCUSSION

Child-led interventions

Making independent decisions is important for children, and children with disabilities get less autonomy

- PDA (Pathological demand avoidance / Persistent Drive for Autonomy) profile
- Extensive amount of interventions

Promoting autonomy and self-advocacy

Preserving childhood

Not targeting autism traits

Wider literature on reducing autistic traits
- Masking / camouflaging -> excessive effort, self-image and confidence

Following priorities of autistic community

LIMITATIONS

- Things happened when the participants were very young.

- Vague definition of concepts (e.g. ABA could mean different things for participants).

- Sample discrepancy in surveys – people who receive interventions are not the same people who fill in surveys

- Very wide inclusion criteria
- We cannot talk about all interventions and all countries (although the research done internationally, most of the participants are from the USA).

- Needed:
- More studies about methods and nuances
- More studies that would capture different perspectives

THANK YOU

Register interest in my next study (autistic parents of autistic children) →

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