

EXAMINING SOURCES OF, AND INTERVENTIONS FOR DISTRESS IN AUTISTIC INDIVIDUALS WITH COMPLEX NEEDS

- A SYSTEMATIC REVIEW OF PROCEDURAL AND MEASUREMENT ISSUES AND PRACTICE

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01 BACKGROUND

Around 40% of autistic people also have complex needs e.g., significant language and/or intellectual differences. This group are particularly vulnerable to mental health conditions and distress, which can have a significant impact upon their quality of life (Park et al, 2019).

The autistic community have identified mental health as a key research area they would like explored (Cusack & Stery, 2016). However, evidence from existing reviews often focuses on a specific aspect of distress e.g., anxiety (Rodgers & Oldfield, 2018), depression (Cameron et al., 2020) and distress-related behaviour (Sawyer et al., 2014) but, it is unclear what forms or patterns of distress are more common.

02 AIMS & QUESTIONS

The aim of this review is to assess research methods and processes used to explore distress-related behaviours in autistic individuals with complex needs.

- How does research define and operationalise ‘distress’ (express or use distress as an outcome measure) and its underpinning causes?
- What approaches have been used to capture distress and its suspected causes?
- What strategies are used for engaging, recruiting and retaining autistic people with complex needs in studies concerning the causes of and interventions for distress?

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03 SEARCH STRATEGY

We used a search strategy to identify studies that have examined distress in autistic people with complex needs

‘Distress’ included internalising mental health conditions e.g., anxiety and depression as well as externalising behaviours e.g., self-injury, aggression or distress-related behaviours that are often associated with unpleasant sensory experiences.

Table 1. Search Terms

Autism	(autis* OR "pervasive developmental disorder*" OR Asperger*)	AND
Complex Needs	("complex needs" OR "intellectual disab*" OR "intellectual impair*" OR "learning disab*" OR "learning impair*" OR "minimally verbal" OR "non-verbal" OR "low functioning")	AND
Sensory/Mental Health	("sensory processing" OR "sensory hypersensitivity" OR "challenging behav*" OR "problem behave*" OR self-injur* OR aggress* OR internal*ing OR external*ing OR "mental health" OR anxiety OR depression OR suicide)	

03 METHOD

Inclusion Criteria

- ✓ Individuals with a diagnosis of Autism Spectrum Disorder and ‘complex needs’
- ✓ Interventions of interest include those directed at improving distress in the target population
- ✓ studies that capture distress through any method, including self or proxy report, direct behavioural observation in controlled or naturalistic settings, or psychophysiological indices (e.g., heart rate, cortisol levels, etc).

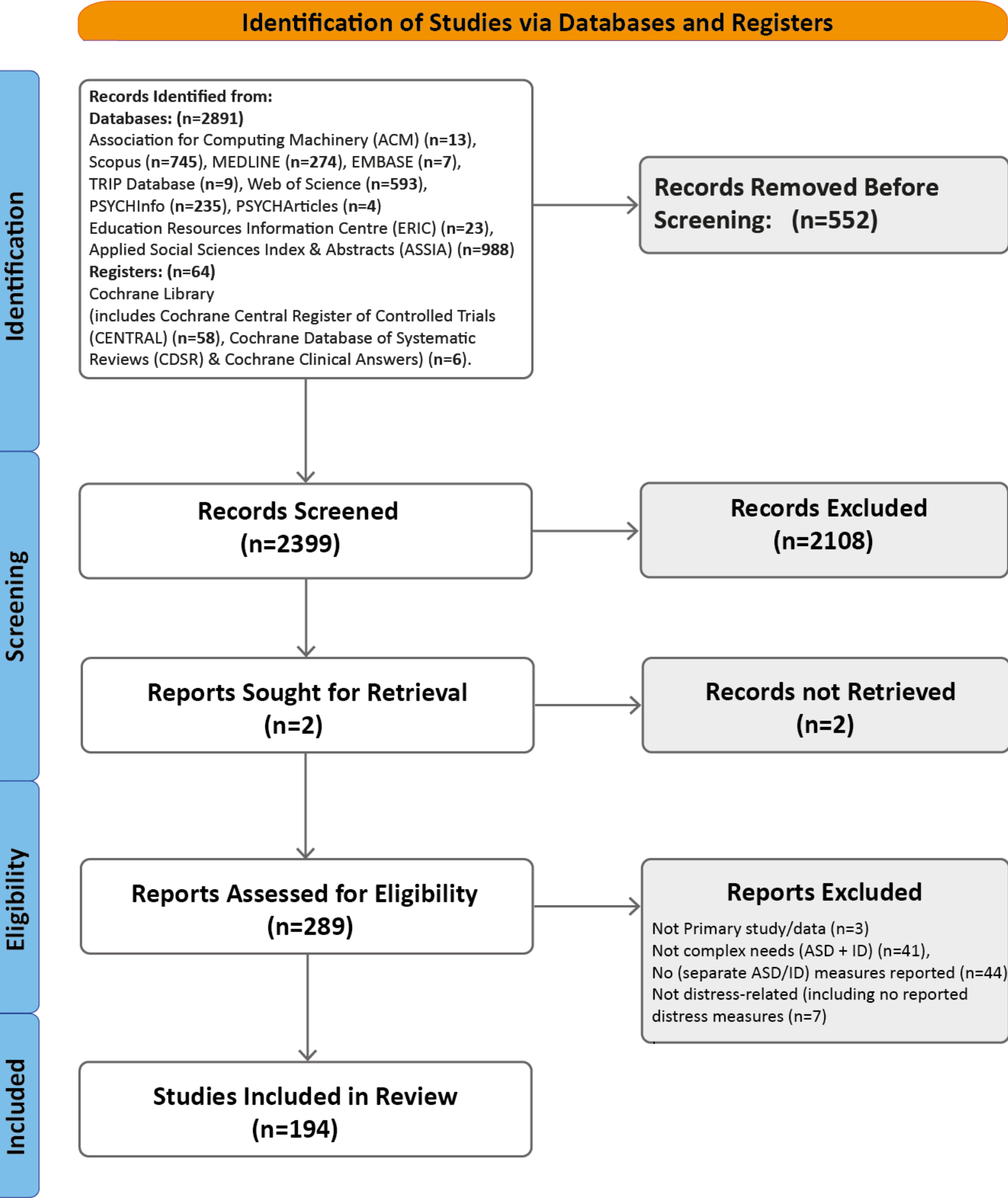
Operationalisation of ID in studies was problematic:

- Difference in measures used
- Heterogenous groups

2399 records were retrieved from 10 electronic databases and 3 registers searched using search strategy.

Screening resulted in 194 studies included in the review.

Figure 2. PRISMA Flow Chart



04 FINDINGS

The main type of distress explored was externalising distress-related behaviour. Internalising behaviour e.g., anxiety and depression were less explored. Other types of distress included psychopathology (10%), phobias (1.6%) and psychosis (1.6%).

In total, 69 different measures were used to operationalise distress. The most used psychometric measures were designed for:

- The general population e.g., Child Behaviour Checklist (CBCL, Achenbach & Rescorla, 2001),
- People diagnosed with Intellectual Disability (ID) e.g., Aberrant Behaviour Scale (ABC, Aman & Singh, 1986)
- Autistic people with ID e.g., Psychopathology in Autism Checklist (PAC, Helverschou et al. 2008, 2009)
- Autistic people e.g., Autism Spectrum Disorders-Behavior Problems for Adults (ASD-PBA, Matson & Rivet, 2007, 2008)

The three most used measures included:

- Frequency of target behaviour
- Aberrant Behaviour Scale
- Challenging Behaviour Checklist

The most used type of measure was proxy report by caregivers (79%) and clinicians (15%). Psychophysiological measures (heart rate, cortisol electrodermal activity) were used less frequently (4%). Observations of distress-related behaviour (1%) and self report measures were very rarely used (1%).

Figure 2. Types of Distress Explored in the Literature

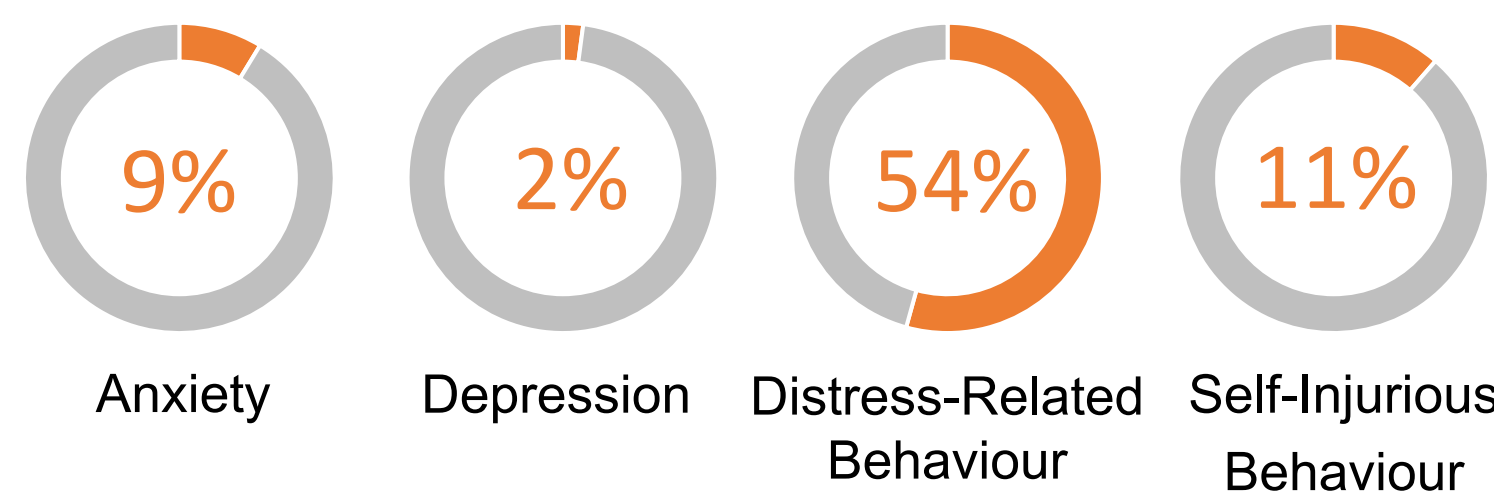


Figure 3. Distribution of Measures by Target Population

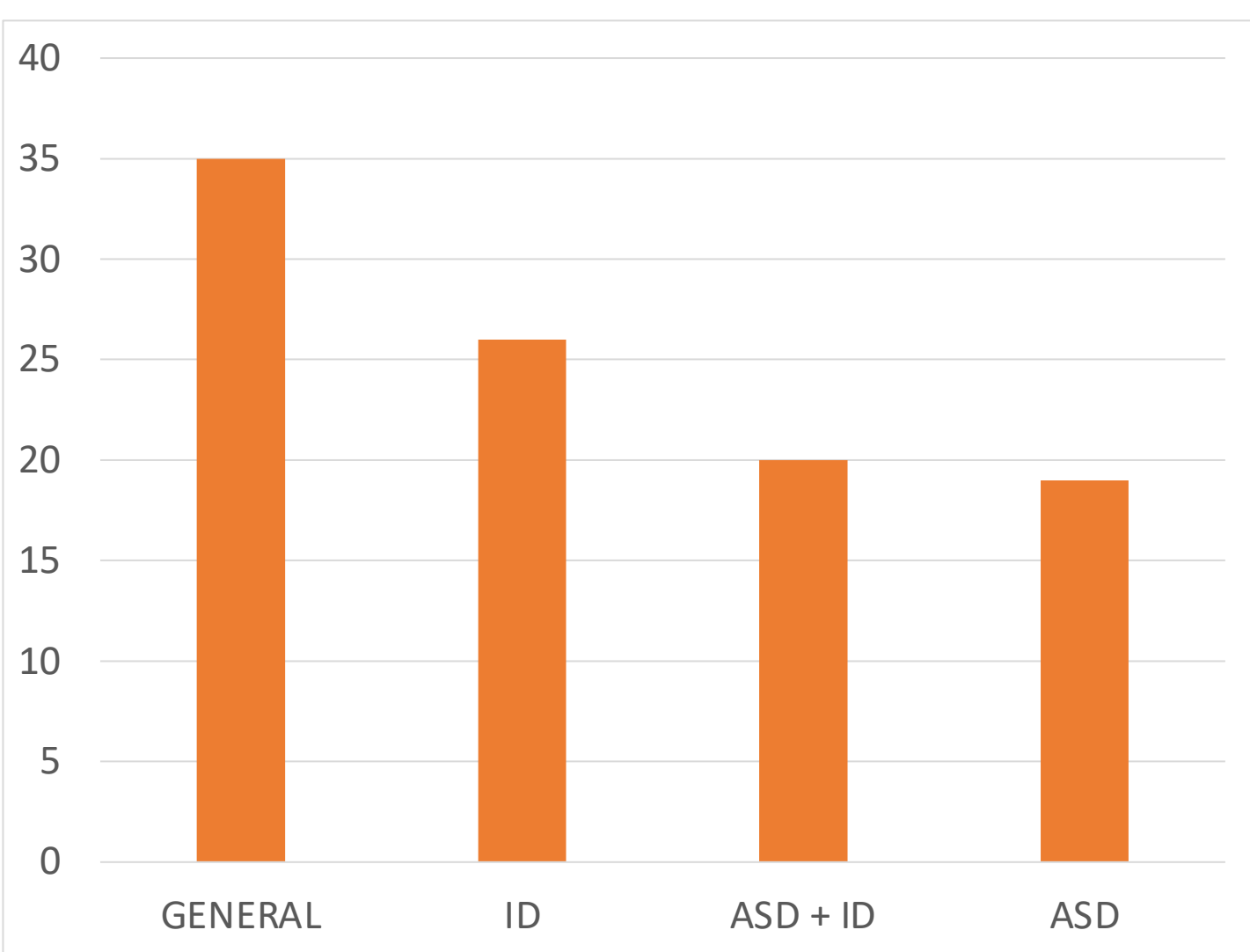
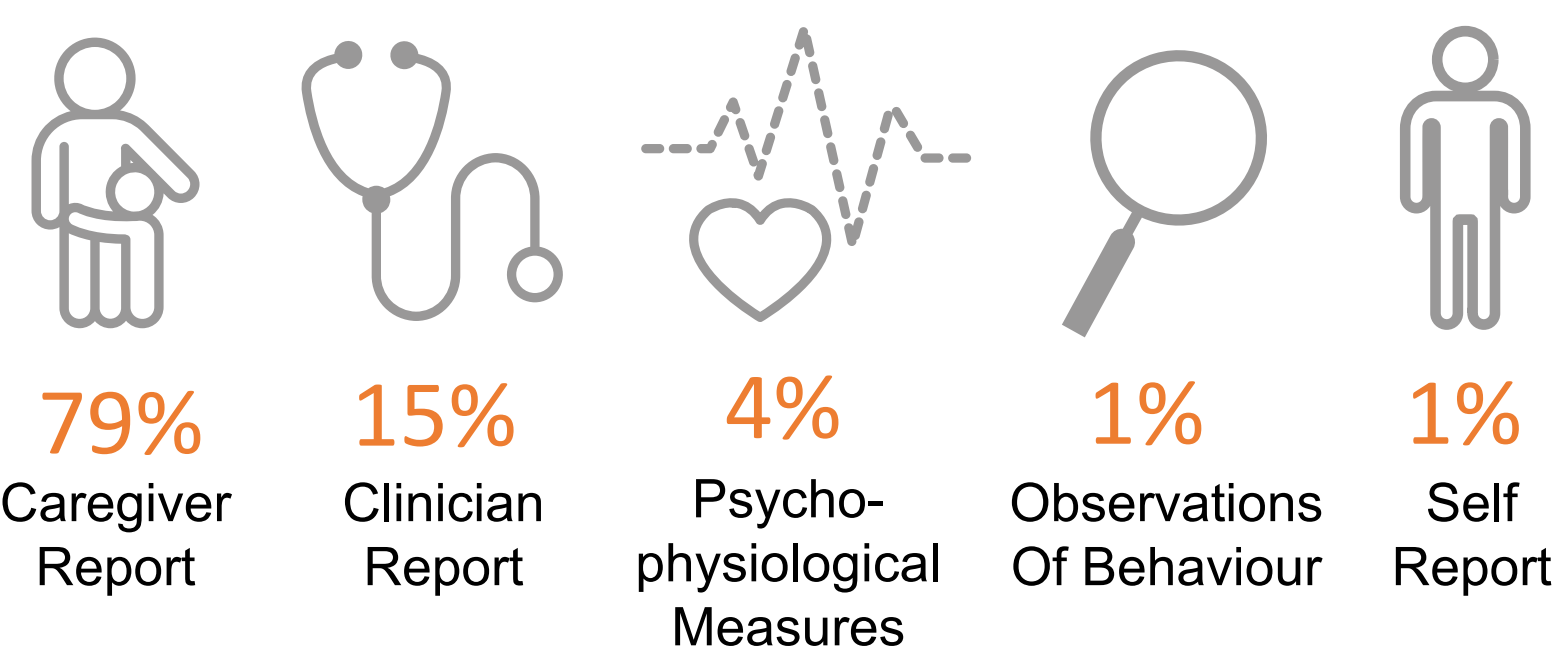


Figure 4. Commonly Used measures of distress



04 FINDINGS CONTD.,

Most studies used a cross sectional design; followed by single case study and case series designs.

There were limited longitudinal, randomised control trials exploring interventions for distress and few qualitative studies exploring the experience of distress.

Figure 5. Study Designs

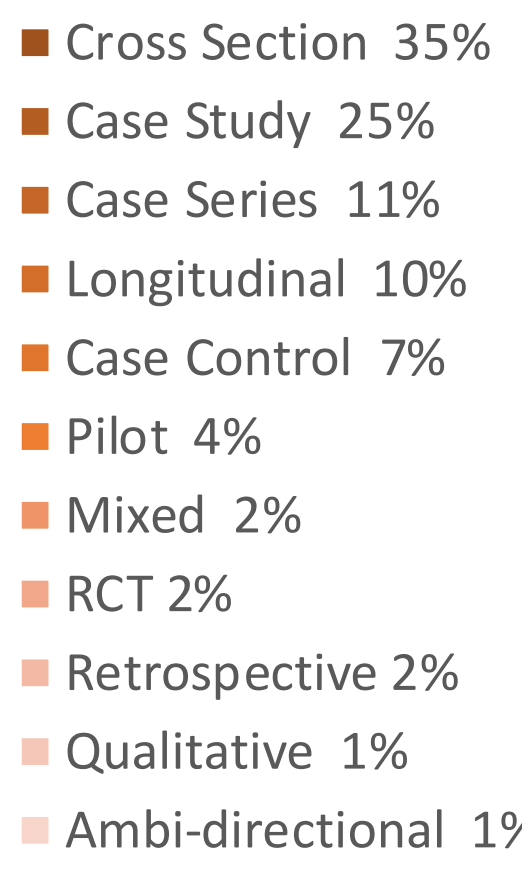
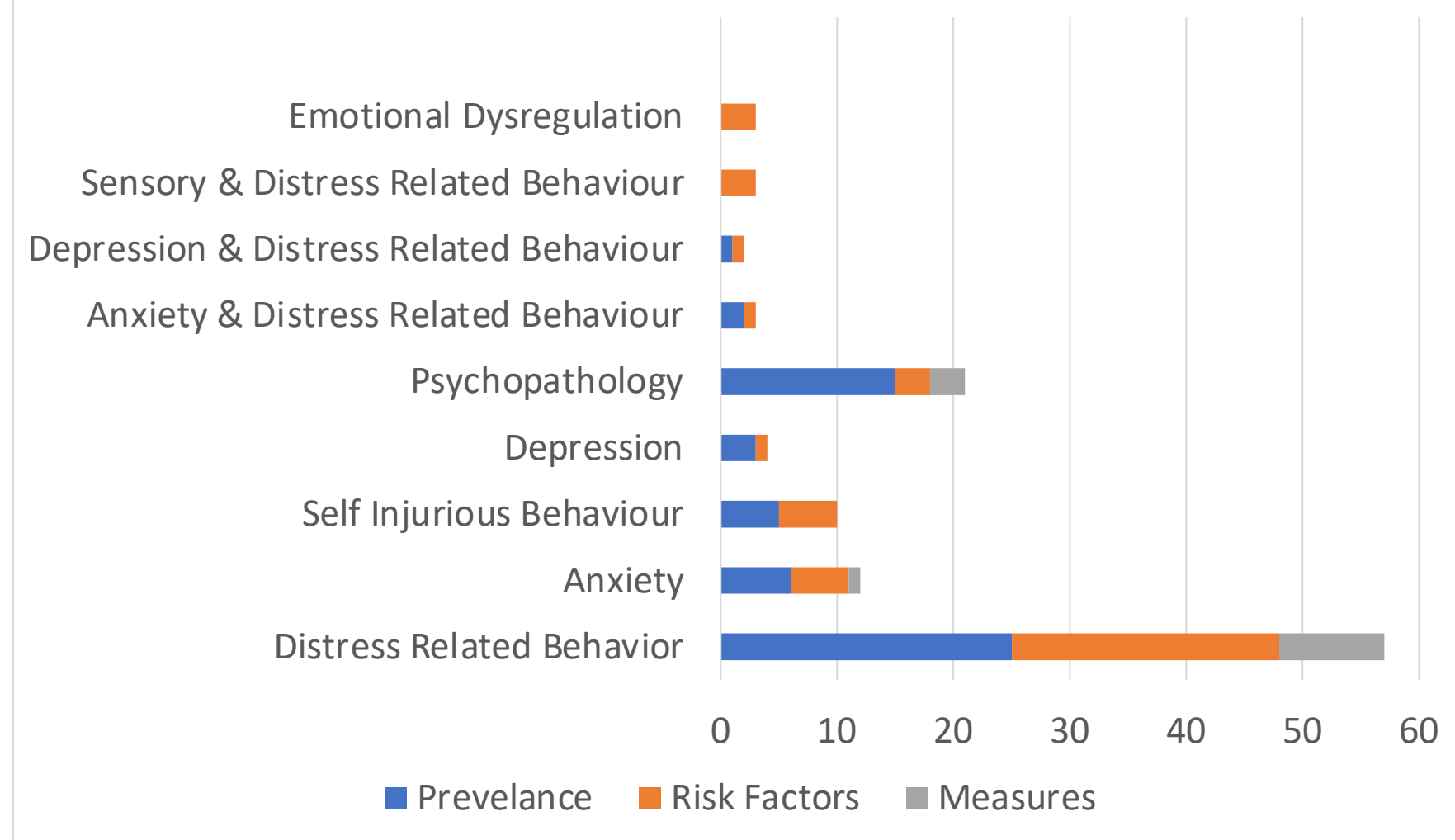


Figure 6. Distribution of Prevalence Studies Across Distress types

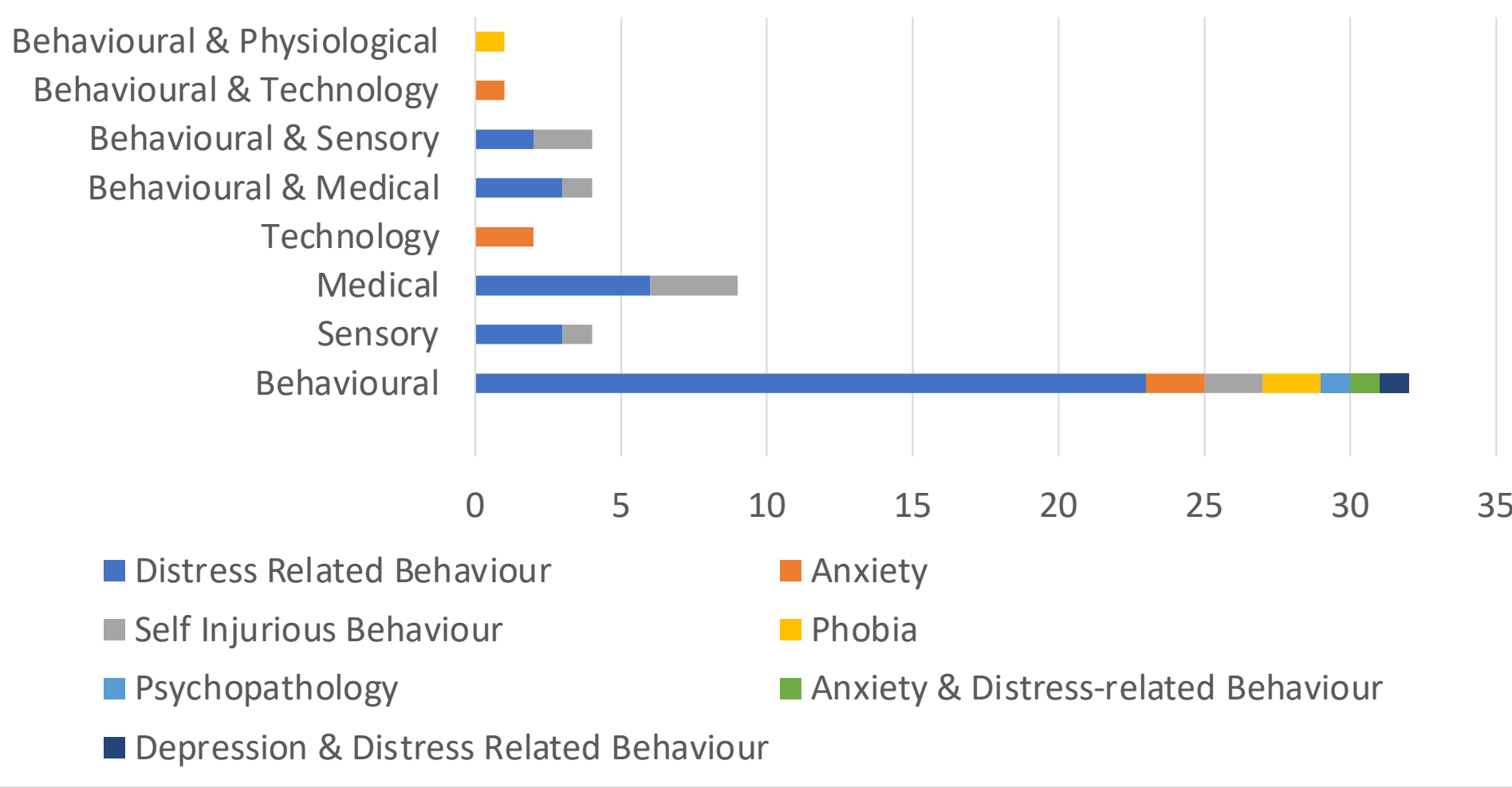


The majority of studies 70% examined prevalence of distress. Studies also explored the potential risk factors or underlying causes of distress. These included:

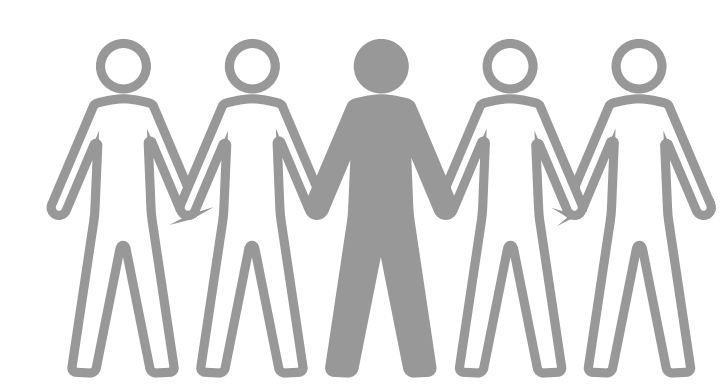
- **Emotional dysregulation,**
- **Atypical sensory processing,**
- **Sleep quality,**
- **Inability to cope with environmental changes,**
- **Anxiety or frustration at poor communication with others.**

Limited studies examined links between types of distress e.g., distress-related behaviour and depression

Figure 7. Distribution of Intervention Studies Across Distress types



30% of studies reported on interventions for distress. The most common type of intervention was behavioural (involving a form of functional behavioural assessment) followed by medical interventions both for distress-related behaviour.



Adaptions made to methods and processes included the use of social stories in obtaining consent and to increase engagement in interventions. Alternative communication aids e.g. PECS were used to help support communication during interventions. Behaviour-based case studies were more likely to tailor interventions and adapt measures to the needs of the patient. Parents and caregivers were involved in selecting measures and supporting interventions.

05 DISCUSSION

- Internalising conditions of distress (particularly depression) are not well explored.
- Limited links are made between different forms of distress.
- Measures used are dominated by proxy report.
- The views and collaboration of autistic people with intellectual disability is underrepresented in distress research.