

Understanding Stress in Autistic People and their Parents

What We Found

Parents and their autistic children all experience serious stress with implications for health and relationships.

Parents of autistic children are consistently more stressed than parents of non-autistic children, including parents of children with disabilities. Stressors arise directly from supporting their child's needs (e.g. atypical communication, risky behaviour, medical care) but also from consequent financial stress, feeling judged by others, and feeling like a bad parent. Stress is exacerbated if friends don't understand or accept their autistic child, limiting social support.

Autistic children often find schools to be a stressful environment, in terms of being bullied, sensory environment, and lack of routine. Children with limited communication options may express their stress in ways interpreted as misbehaviour, resulting in punishment, which causes further stress. Relationships with other children are a major source of stress, especially for those children who are self-conscious of being different. Loneliness causes stress, as can socialising, resulting in a vicious cycle of stress.

Experimental studies of stress, where people are exposed to something stressful and their reaction – e.g. their heart rate – is monitored, are equivocal in terms of whether autistic children have an elevated stress response or not. In one study, even though biological information wasn't different between groups, autistic people reported feeling more stressed – suggesting that experience of stress can be raised even if it isn't detectable biologically.

Both parents and their autistic children experience poor mental health as a result of stress, and their stress may also negatively shape the parent-child relationship. For children, stress can also prevent access to learning and friendships, and result in rumination – going over bad things again and again – and problems with sleep.

What We Suggest

Both being autistic and being a parent of an autistic child is stressful and this stress can easily be exacerbated by service inaccessibility.

Services should be aware of a significant burden of stress carried by parents and their autistic children. Services should work hard not to add to this stress by:

- Making resources and support as accessible as possible
- Avoiding placing unrealistic deadlines for responses
- Recognising the ways in which vicious cycles of stress can develop via impact on relationships and social support

In understanding and responding to stress, we should be careful not to pathologise a reasonable response to a stressful situation. The solution to parent stress is not therapy for their autistic children, but financial, social and professional service support. Likewise, when autistic children experience stress this should not be discounted as an inevitable feature of autism, rather than a response to a stressful environment.

What We Did

Two systematic reviews were carried out, by a pair of undergraduate students, to look at the causes, consequences and manifestations of stress in autistic people versus in the parents of autistic children.

Parent stress has been studied more extensively than the stress experienced by autistic people themselves.

We found thousands of results and screened them for relevance, resulting in:

- 23 relevant papers reporting on stress in autistic people, mostly children but also some with adults
- 31 relevant papers reporting on stress in parents of autistic children

The volume of research conducted on parents of autistic children was higher in number of studies, and number of participants, than research reporting on autistic children or adults.

Most studies use self-report questionnaires to estimate how stressed people are and what the causes and consequences might be. There is a small amount of longitudinal data, charting stress over time.

There was a handful of studies using experiments to see how people respond to a stressor, and then measuring heart rate or cortisol (“the stress hormone”). However the results were very variable as was their interpretation.

Why We Did It

It is a relatively common public perception that parenting or caring for an autistic child is a stressful experience. Much research focuses on quantifying parent stress and examining the specific causes and consequences of that stress [1].

The focus on parent stress and comparatively little attention paid to autistic people’s stress warrants a comparative exploration of what is known in those two groups.

However, it is not clear that similar research attention has been paid to stress in autistic individuals themselves. This is despite the fact that autism is commonly associated with a wide variety of mental health problems [2], meaning that the consequences of stress for autistic people may be severe.

There is debate regarding prioritisation of research in the autism community – comprising autistic people, their parents and others who are connected, such as practitioners [3]. The autistic community has historically not been consulted in research development, and there is growing belief that the autism research literature does not reflect wider requirements of autistic people or their caregivers [4]. As a result, there is a need to review existing literature to evaluate its relevance and identify potential gaps.

Thank you

1. Ghanouni, P., & Hood, G. (2021). Stress, coping, and resiliency among families of individuals with autism: A systematic review. *Review Journal of Autism and Developmental Disorders*, 8, 389-402
2. Lai M-C, Kasseh C, Besney R, et al. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry* 2019;6:819–29. doi:10/ggs5wj
3. Clark, M., & Adams, D. (2020). Listening to parents to understand their priorities for autism research. *PLoS one*, 15(8), e0237376
4. Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M. L., ... & Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, 24(4), 822-833

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