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Autistic mothers of autistic children: A preliminary study in an under-researched area

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Short title: [Outcomes for autistic mothers of autistic children](#)

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Abstract

Background: Much research exists on the mental health and well-being of parents of autistic children; however, parents who are themselves autistic have received little attention in the literature. The aim of the current study was to compare parenting stress and family outcomes in mothers who do, and do not, identify as being autistic.

Methods: Twenty mothers who identified as being autistic were matched to twenty mothers who do not identify as being autistic on variables associated with parental well-being: child externalising behaviours, score on the Social Communication Questionnaire, child adaptive functioning, family income, and child and maternal age. All mothers had at least one autistic child. Outcome variables were family outcomes (Family Outcome Survey-Revised) and parenting stress (Parent Stress Index 4-Short Form). Paired t-tests were used to compare scores between the two samples.

Results: With one exception, there were no differences in achievement of family outcomes between the autistic and non-autistic mothers. The exception was the small effect size on Family Outcome 4 which indicates that autistic mothers may develop stronger support networks. Autistic and non-autistic mothers report equally high levels of parenting stress.

Conclusions: Further work is needed to explore this under-researched area. Such research would be of value to understand any interaction between parental and child autism characteristics, well-being, and parenting, and could inform development of supports which can be tailored for each child's family.

Lay abstract

Why was this research done?

Despite decades of research exploring well-being and mental health of parents of autistic children, plus the recognised higher prevalence of autism within families, the experience of autistic adults with autistic children has not been researched very often. In fact, the researchers could find less than five research studies on the topic.

What was the purpose of the study?

This study wanted to do some preliminary work in the area, and look at whether parent well-being or family outcomes are different or similar between autistic and non-autistic mothers of autistic children.

What did the researchers do?

The researchers are working on a large longitudinal study (on a different topic) with 270 autistic children across Australia. As part of this study, the researchers asked parents about their own experiences and well-being, which included questions on whether or not the parents identify as autistic. This meant that within this larger study, there was the data to look at parent and family outcomes and see if they differ depending on whether or not the mother themselves identified as being autistic.

To do this, the researchers went to the large dataset and firstly identified the mothers who identified as being autistic; this was 20 mothers. Then, they carefully matched the 20 autistic mothers to 20 mothers who did not identify as autistic (non-autistic mothers) on a number of areas that previous research has linked with parent and family well-being and outcomes. This was a long but important step, as making sure that the two groups were as similar as possible on the areas that shown to impact parent and family outcomes means that you can be more confident that any differences between the two groups are due to the one thing that is purposefully different between the two groups: whether or not the mothers were autistic.

What were the results of the study?

The results show in general, parent well-being and family outcomes did not differ between the two groups. In fact, the results suggest that autistic mothers may develop stronger support networks than non-autistic mothers. However, this finding needs to be explored with larger samples.

What were the potential weaknesses of the study?

The small sample size and the lack of detailed knowledge around parental relationship status and ethnicity mean that it isn't possible to assume that these results represent the wider population

How will these findings help autistic adults now or in the future?

It is hoped that this study will be a platform to inspire future research in this area, using different research methods (interviews, questionnaires) to learn from the lived experience of autistic mothers. This can provide a way for non-autistic parents, researchers and professionals to learn from the experience and skills of autistic mothers and potentially inform future practice.

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Introduction

Despite autism being a lifelong condition, only 2% of research funding is allocated to lifespan research.¹ As recently as 1988, researchers questioned whether autistic adults could "...marry, have satisfactory sexual relations, have children, [and] hold regular jobs"². (p139) With the realisation that autistic children grow into autistic adults, an increasing number of adults are being diagnosed as autistic and having children of their own. However, little is known about the experiences of autistic parents. As autistic individuals are more likely to have autistic children,³ careful methodology is required to explore both positive and challenging experiences that parenting can bring and identify the relative contribution, if any, of parent, child, environmental and systematic factors (and their interaction) to these experiences⁴. The aim of this research was to compare family outcomes and parenting stress in mothers of autistic children who themselves do and do not identify as being autistic.

Little research exists however, directly exploring the parenting experiences of autistic parents. In a recent newspaper article that included interviews with autistic parents, Deweerdt⁵ summarised that being an autistic parent can provide helpful parenting skills, particularly when their child is also autistic, but that it can also be challenging at times, for example when dealing with one's own sensory sensitivities or when one needs or wants to help their child understand a complex social situation. Lau and Peterson⁶ explored parental satisfaction in 22 autistic adults, whose children were also autistic. They found that being autistic or having a spouse who is autistic did not significantly decrease satisfaction derived from parenting roles. However, parents of autistic children reported lower parental satisfaction than parents of non-autistic children. Lau et al.⁷ compared self-reported parental efficacy among three groups: group 1: 109 parents and their children who were both autistic, group 2: 128 non-autistic parents of autistic children, and group 3: 109 non-autistic parents of non-autistic children. Autistic mothers reported comparable reported levels of parenting efficacy to non-autistic mothers in both groups. However, autistic fathers of autistic children (group 1) reported significantly lower parental efficacy than non-autistic fathers in groups two or three. This suggests that the experience of parenting for autistic parents may differ, and that other factors, including whether or not the child is autistic, may interact with that experience.

Pohl et al.⁸ explored the experiences of 355 autistic mothers and 132 non-autistic mothers, all of whom had at least one autistic child. Autistic mothers were more likely than non-autistic mothers to report pre- or post-natal depression, difficulties in parenting (e.g., multitasking, coping with domestic responsibilities, creating social opportunities for their child), and feeling misunderstood by professionals. They were also more likely to find motherhood an isolating experience, to worry about others judging their parenting, or to feel unable to turn to others for parenting support. The authors conclude that motherhood in autistic women is a neglected area of research and more work is needed to further understand any unique challenges that autistic mothers may face.

Dissanayake et al.⁴ noted that higher autism traits within parents of autistic children were correlated with lower parenting satisfaction and higher reported parenting difficulties (accounting for 11% of variance) such as understanding their child's needs, regulating emotions related to their child, and dealing with sensory stimuli. However, parental autism traits did not contribute to parental psychological well-being. Such broad and mixed results around both strengths and challenges for autistic parents highlights a clear need for more work in this area to begin to understand the potential relationship (if any) between parent diagnosis, child diagnosis, and parental mental health and well-being.

In addition to exploring the relationship between child and parent characteristics and parenting well-being, research has begun to focus on the outcomes of families of individuals with additional needs. Bailey et al.⁹ define family outcomes as, "benefits experienced by families as a result of services received" (p228) – specifically, understanding the needs and abilities of their children, awareness of their rights, helping their children learn and develop, having support systems, and accessing the community²¹, and several recent studies have reported on family outcomes for families of autistic children^{10,11}. This is particularly important in mothers on the spectrum given that Pohl et al.⁸ reported that mothers on the spectrum had significantly more difficulty than non-autistic mothers in feeling able to communicate effectively with professionals about their child, and were more likely to feel misunderstood by professionals and to feel unable to turn to others for support in parenting. Given the mixed findings for well-being outcomes in autistic mothers of autistic children, it is critical that any approach to exploring differences in the achievement of family outcomes between autistic and non-autistic mothers is able to consider the benefits of being an autistic mother of an autistic child alongside any additional challenges that this may bring.

Summary and Research Questions

Autistic children grow up to be autistic adults, who may themselves become parents. The very limited research literature to date exploring the experience of autistic mothers of autistic children suggests that being an autistic parent of an autistic child may bring many benefits but maybe also some challenges which requires further research. The aim of this study was to therefore explore family outcomes and parenting stress in autistic and non-autistic mothers of autistic children. The following research questions were asked:

1. Are there differences in family outcomes in families of autistic children where the mother does and does not identify as being autistic?
2. Are there differences in levels of parenting stress between mothers of autistic children who do and do not identify as being autistic?

Given the limited literature in the area, no directional hypotheses were made.

Methods

Procedure and design

The study utilised data from the Longitudinal study of Australian Students with Autism (LASA); an initiative of the Co-operative Research Centre for Living with Autism established and supported under the Australian Government's Cooperative Research Centres Program. The LASA is a cross-sequential prospective longitudinal quantitative study wherein data regarding educational and participation outcomes were collected annually over 6 years (for detail, see published protocol¹²). Upon enrolment, caregivers were asked to provide documentation of their child's DSM-IV or DSM-V^{13, 14} autism diagnosis and then completed the Social Communication Questionnaire (SCQ).¹⁵

Participants and matching procedure

The current study used data collected at time of enrolment for the larger longitudinal study. At enrolment, parents were asked to respond *yes* or *no* to a question asking whether they themselves have a formal diagnosis of autism. Twenty mothers stated that they identified as being autistic. These mothers were matched to a sample of mothers from the remaining 200 complete datasets who did not identify as being autistic at the time of the questionnaire (hereafter referred to as non-autistic). For demographics of the sample see Table 1.

++Insert Table 1 here++

As seen in Table 1, both groups of participant mothers were generally well-educated, with 72.5% of the total sample having a tertiary education. The 2016 Australian census data (the year that this data was collected) reported the median annual household income as AUD\$74,776, meaning that 65% of autistic mothers and 80% of non-autistic mothers were living in households with income above the national median. More than three times as many autistic mothers (50%) had received a diagnosis of a mental health disorder in their lifetime than non-autistic mothers (15%), a difference that was statistically significant. Most mothers in the autistic (70%) and non-autistic (90%) were enrolled into the LASA study for their male child. Although not statistically significant, 30% of autistic mothers had enrolled into the LASA study for their autistic daughters compared to only 10% of the non-autistic mothers.

As the aim of the study was to explore the family outcomes and parenting stress levels between the two groups, a close matching procedure (as per Ambrose et al.¹⁶) was undertaken. This aimed to control for factors previously shown to be associated with family outcomes or parent well-being within the autism and intellectual disability literature and therefore reduce the possibility of any group differences being due to those factors. It is important to note that whilst these factors have been shown to be associated with parenting stress, this does not imply that they are the direct cause of increased levels of parental stress. As parental stress has been shown to be higher in children who are showing higher level of behavioural challenges^{17,18,19} or have less developed adaptive behaviour skills^{20,21}, both of these factors were matched between the groups. Levels of parental stress has also been shown to be higher in younger parents²² and in parents living in households with a lower income²³, so maternal age and family income was also matched as close as possible between the two groups. Following matching, no significant differences were found between autistic and non-autistic mothers in terms of matching variables, indicating these groups may be comparable (see Table 1).

Measures

Matching variables.

The Disruptive/Antisocial Behaviour scale of the Developmental Behaviour Checklist-Parent/carer Form (DBC-P)²⁷ was for the number of behavioural challenges. Items are summed for a total score that shows excellent internal consistency, $\alpha = .94$.²⁴

The Social Communication Questionnaire – Lifetime (SCQ)¹⁵ was firstly used to verify children’s autism diagnosis and then used as a matching variable between the two groups. The total score shows good internal consistency, $\alpha = .81$.²⁵

The Receptive Communication subdomain of the Vinelands Adaptive Behavior Scale, 2nd edition (VABS-II).²⁶ The V-scale score (i.e., standardised score) was used for analysis as per Giovagnoli et al.¹⁸ and shows good psychometrics including acceptable internal consistency $\alpha = .84 - .93$.²⁶

Outcome variables.

Family outcomes: The Family Outcome Survey-Revised (FOS-R),²⁷ Section A, has five subscales: (1) understanding their child’s strengths, abilities, and needs; (2) knowing their rights and advocating for available services; (3) helping their child learn and develop; (4) having support systems; and (5) accessing the community. Items are rated on a 5-point Likert scale. For the current sample, Section A showed good internal consistency, $\alpha = .87$ (Outcome 1), $.91$ (Outcome 2), $.93$ (Outcome 3), $.88$ (Outcome 4), and $.79$ (Outcome 5).

Parenting stress: The Parent Stress Index 4-Short Form (PSI-SF).²⁸ The Parent Distress (PD) subscale, Parent-Child Dysfunctional Interaction (PCDI) subscale, and total stress score were calculated. For the current sample, the PSI-SF had good internal consistency, $\alpha = .87$ (PD), $\alpha = .85$ (PCDI), and $\alpha = .93$ (total stress).

Data screening and analysis

Data from one participant was missing for one FOS-R item (< 5% missing data); mean value substitution was used in order to calculate the overall mean for Outcome 2 as is recommended.²⁹ Exploration of skew and kurtosis suggested a distribution within the normal range. Given the high degree of matching between the samples (see Table 1), the two samples were not considered independent of each other, so paired samples t-tests were used to compare scores on each subscale.

Effect sizes are calculated and presented so as to quantify the size of any difference between the two groups without being confounded by sample size. Within a study with a limited sample size such as this, there is an elevated probability that the p value may be “not significant” due to the sample size and low power of the study rather than there being no difference between the two groups. Therefore, by reporting on and interpreting the results based on effect size, it is possible to quantify the magnitude of any difference between the groups and therefore reducing the risk if a type II error (i.e. a false negative).

For effect size, Cohen's d was considered to be small (0.2-0.49), medium (0.5-0.79), or large (>0.8)³⁰. Anything below 0.2 is considered to reflect a "trivial" difference between groups³⁰. A small effect size suggests that there is a real effect (i.e. something differs between the two groups) but one that can only be identified through careful study and one that will only be identified as "statistically significant" with large sample sizes³⁰. However, a small effect size may mean that the difference may not be clinically noticeable in the real-world at an individual level (i.e. it may only be noticeable at a group level with greater intra-group than inter-group differences).

Results

Family outcomes

As shown in Table 2, there were no significant differences between groups on Outcome 1 (understanding child's strengths, abilities, and needs), Outcome 2 (knowing rights and advocating for services), Outcome 3 (helping child learn and develop) and Outcome 5 (accessing the community). For these outcomes, the effect size was below the cut-off for a small effect size (i.e. only indicates a "trivial" difference between groups).

The comparisons for Outcome 4 (having support systems) had a small effect size, indicating that there may be genuine difference between the two groups. However, most likely due to sample size, the paired t-test comparisons did not identify a statistical significance between the two groups.

++Insert Table 2 about here++

Parenting stress scores

As noted in Table 2, there was no significant difference and below small effect sizes (i.e. trivial differences) between PSI-SF total score, PD, and PCDI scores between the two groups.

Discussion

This study aimed to explore whether there was a difference in the levels of family outcomes and parenting stress between mothers who do and do not identify as autistic. Mothers of autistic children were matched on factors which have previously been identified as being associated with parental well-being (child challenging behaviours, score on the SCQ, adaptive functioning, family income, and child and maternal age). The use of control groups is critical to furthering the understanding of the similarities and differing experiences of women on the spectrum³¹. With the exception of Family Outcome 4 (Having support systems) which is discussed further into the discussion, there were no significant differences

and “trivial” effect sizes in mean scores on measures of family outcomes and levels of parenting stress between mothers who did and those who did not identify as being autistic. These findings provide a clear example of where a nonsignificant result (along with trivial effect sizes suggesting a lack of meaningful differences between groups) provides clinically important information. It highlights that when controlling for the known factors associated with maternal well-being between the two groups (e.g., child challenging behaviours), the additional factor of maternal autism diagnosis status did not significantly increase or decrease the levels of parenting stress or (with one exception) change family outcomes. Therefore, negative parental outcomes should not be assumed based on parental diagnosis.

The results of the current study are consistent with previous research that found autistic mothers reported similar levels of parental satisfaction⁶ and parental efficacy⁷ as non-autistic mothers. Pohl et al.⁸ conclude that autistic motherhood may be a different experience, although the factors which Pohl et al. identify as the main differences between mothers who are and who are not on the spectrum (difficulties in parenting, finding parenthood isolating, experiencing pre- or- post-natal depression, and feeling misunderstood by professionals) are unlikely to be captured on the measures of parenting stress or family outcomes. This highlights the importance of careful consideration of the factor being measured and not assuming that because some aspects of motherhood are reported to be challenging, that this will be reflected in all measures explored. Of course, it may be that some of the variables controlled in the current study (e.g., child challenging behaviour) also controlled for some of the factors which are associated with experiences such as parenting difficulties and social isolation.

As noted in a recent editorial,³⁰ statistical group comparisons do not tell the whole story, and there is a need to complement this work with voices of autistic mothers using qualitative methods. Knowing, accepting, and celebrating that you have the same diagnosis as your child (and therefore share a number of characteristics) may allow autistic mothers to feel that they have a greater understanding of themselves and how they can relate to their children⁵ and ensure a greater support system. This may be one factor that contributes to the small effect size noted for Family Outcome 4, Having Support Systems. On this Family Outcome subscale, a higher percentage of autistic mothers (70%) reported that they had good support systems than non-autistic mothers (45%). These questions ask about having family and friends who understand their child's needs and who have children with similar needs, and about those who care. A small effect size coupled with a non-significant p-value within a study with a small sample size, such as this, suggests that the difference may be present but

larger samples are required for detection³⁰. A post-hoc power analysis with the effect size of FOS-R Outcome 4 ($d = 0.31$) suggests that a sample size of at least 90 mothers in each sample would be needed for future work using a quantitative approach to explore Family Outcomes or similar constructs. This highlights the work for more research with larger samples to further understand this area and exploring how autistic mothers develop these support networks and what may make them more useful or powerful for them. However, it should be noted, an effect of this magnitude may represent a small difference detected at a group level only, so clinically it may have limited value on an individual basis. This highlights the importance of understanding each individual to inform clinical support or needs, rather than making assumptions based on diagnosis or non-diagnosis.

Although not an aim of this study, the finding that more than three times as many autistic mothers than non-autistic mothers had received a diagnosis of a mental health disorder in their lifetime is worthy of note and discussion. Elevated levels of mental health diagnoses are reported in autistic adults³² with recent work³³ (Sedgewick, Leppanen & Tchanturia, 2020) highlighting that autistic women and non-binary people in particular experienced mental health issues at higher rates than autistic men. It is not known when or how the autistic mothers in this study were diagnosed as autistic, but the elevated levels of mental health diagnoses across the lifetime may also reflect an increased risk of being misdiagnosed with a mental health problem, perhaps prior to receiving their autism diagnosis³⁴. Such findings highlight the importance of further understanding the multiple and intersecting journeys that many autistic mothers may have been on and how they have come together now in their role as an autistic mother of an autistic child.

Limitations and future directions

The current study was one of the first to examine family outcomes and parenting stress of autistic mothers within the same study. There is very little existing research exploring the parenting experiences of autistic parents. As data were extracted from an existing dataset, rather than specifically recruited for a study on parenting stress or family outcomes, this sample may be more representative. Conversely, mothers who felt able to commit to completing an annual questionnaire as part of the larger longitudinal study may be less stressed overall. Mothers in the sample were generally well-educated and 72.5% were living in households with income above the national median, potentially limiting the representativeness of this sample and the generalisability of findings. As data on ethnicity or marital status were not collected, it is also not possible to comment on how generalisable the sample were in

relation to these variables. As such, future research should seek to gather a more diverse sample and collect this data and report it in future research .

While this study makes an important and novel contribution to understanding family outcomes in autistic mothers, a number of limitations exist. First, the sample size was small and limited due to the use of pre-existing data. Effect sizes (which indicate the magnitude or size of difference between the groups without being impacted by sample size) suggest minimal meaningful group differences, with a small effect only detected for Family Outcome 4. Future research could build on this study using a larger sample size which then would also allow for investigation of whether the predictors of parenting stress or family outcomes differ between the two groups, even if absolute values of parenting stress are similar. Such research could inform future support for parents and families of autistic children.

Mother participants in the current study were not required to verify their autism diagnosis or non-diagnosis. It is possible that some mothers who did not identify as autistic at the time of this questionnaire may be autistic. Furthermore, all of the participants in the study were mothers and results cannot be generalised to fathers, who may show different results as some research shows the parenting experiences of autistic mothers and fathers can differ.⁷ Future research with autistic mothers and autistic fathers could elucidate both similarities and differences between diagnosis groups as well as the impact of gender to ensure both mothers and fathers can receive appropriate support or intervention if needed. There is a clear need to combine qualitative and quantitative methods to further our knowledge of the experience of being an autistic parent of an autistic child, not only in relation to maternal outcomes (such as those explored in this study) but also in relation to other broader systemic factors such as accessing and benefitting from formal or informal supports across the child's lifetime. These combined qualitative and quantitative approaches could also be used to explore whether there are parenting skills or practices that autistic mothers use more, less or differently and whether such approaches which may support or promote positive maternal and/or child outcomes. Such an approach would then enable non-autistic parents and professionals to learn from the experience and skills of autistic mothers and potentially inform future practice.

Conclusion

The current study is one of the first to explore the experiences of autistic mothers and is particularly novel in addressing family outcomes in and parental well-being. With one notable exception, the results showed no significant differences in achievement of family outcomes or levels of parenting stress

between autistic and non-autistic mothers on the parenting autistic children after close matching on a number of variables. The one exception was the Family Outcome around support systems which showed a small effect size indicating at a group level autistic mothers may have slightly stronger or more beneficial networks who understand their child's needs and who have children with similar needs. Our results highlight the importance of not assuming greater parenting challenges for autistic mothers and the need for accessible and effective support for all parents.

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Authorship Confirmation Statement

Dawn Adams: DA has been involved in the management and supervision data collection for the larger study from which this data is drawn since 2016. DA also co-designed this study, carried out the analyses, reviewed and revised the first draft of the manuscript and finalized the manuscript for submission.

Madeline Stainsby: MS conceptualised and co-designed the study, conducted the literature review and interpretation of the results, drafted the first draft of the manuscript, critically reviewed the manuscript, and approved the final manuscript as submitted.

Jessica Paynter: JP was involved in the development and ongoing management of the larger study from which this data is drawn. JP also co-designed the study, critically reviewed the manuscript, and approved the final manuscript as submitted.

All authors have approved the manuscript and agree to its submission to your journal. This manuscript has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

Author Disclosure Statements

Dawn Adams declares that no competing financial interests exist with respect to this publication.

Madeline Stainsby declares that no competing financial interests exist with respect to this publication.

Jessica Paynter declares that no competing financial interests exist with respect to this publication.

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References

1. Wise EA. Aging in Autism Spectrum Disorder. *Am J Geriatr Psychiatry*. 2020;28(3):339-349. <https://doi.org/10.1016/j.jagp.2019.12.001>
2. Ritvo ER, Brothers AM, Freeman BJ, Pingree C. Eleven possibly autistic parents. *J Autism Dev Disord*. 1988;18(1):139-143. <https://doi.org/10.1007/bf02211824>
3. Sandin S, Lichtenstein P, Kuja-Halkola R, Larsson H, Hultman CM, Reichenberg A. The familial risk of autism. *JAMA*. 2014;311(17):1770-1777. doi: 10.1001/jama.2014.4144.
4. Dissanayake C, Richdale A, Kolivas N, Pamment L. An exploratory study of autism traits and parenting. *J Autism Dev Disord*. 2019:1-14. <https://doi.org/10.1007/s10803-019-03984-4>
5. Deweerdt S. The joys and challenges of being a parent with autism. 2017. <https://www.theatlantic.com>
6. Lau W, Peterson CC. Adults and children with Asperger syndrome: exploring adult attachment style, marital satisfaction and satisfaction with parenthood. *Research in Autism Spectrum Disorders*. 2011;5(1):392-399. <https://doi.org/10.1016/j.rasd.2010.06.001>
7. Lau W, Peterson CC, Attwood T, Garnett MS, Kelly AB. Parents on the autism continuum: links with parenting efficacy. *Res Autism Spectr Disord*. 2016;26:57-64. <https://doi.org/10.1016/j.rasd.2016.02.007>
8. Pohl AL, Crockford SK, Blakemore M, Allison C, Baron-Cohen S. A comparative study of autistic and non-autistic women's experience of motherhood. *Mol Autism*. 2020;11(1):1-12. <https://doi.org/10.1186/s13229-019-0304-2>
9. Bailey DB, Bruder MB., Hebbeler K, et al. Recommended outcomes for families of young children with disabilities. *J Early Interv*. 2006;28:227-251. <https://doi.org/10.1177/105381510602800401>
10. Adams D, Keen D, Heussler HS, Wicks R, Roberts J. Family outcomes for families of 4–5-year-old children on the autism spectrum who have received early childhood intervention in Australia. *Infants & Young Children*. 2019;32(3):186-200. <https://doi.org/10.1097/IYC.0000000000000143>
11. Wicks R, Paynter J, Adams D. Exploring the Predictors of Family Outcomes of Early Intervention for Children on the Autism Spectrum: An Australian Cohort Study. *Journal of Early Intervention*. 2019:1053815119883413. <https://doi.org/10.1177/1053815119883413>

12. Roberts JM, Adams D, Heussler H, Keen D, Paynter J, Trembath D, Westerveld M, Williams K. Protocol for a prospective longitudinal study investigating the participation and educational trajectories of Australian students with autism. *BMJ Open*. 2018;8(1).
<http://dx.doi.org/10.1136/bmjopen-2017-017082>
13. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders-IV-TR*. Author; 2000.
14. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders* 5th ed. Author; 2013.
15. Rutter M, Bailey A, Lord C. *The Social Communication Questionnaire: Manual*. Western Psychological Services; 2003.
16. Ambrose K, Adams D, Simpson K, Keen D. Exploring profiles of anxiety symptoms in male and female children on the autism spectrum. *Res Autism Spectr Disord*. 2020;76:101601.
<https://doi.org/10.1016/j.rasd.2020.101601>
17. Bonis S. Stress and parents of children with autism: a review of literature. *Issues Ment Health Nurs*. 2016;37(3):153-163. <https://doi.org/10.3109/01612840.2015.1116030>
18. Giovagnoli G, Postorino V, Fatta LM. Behavioral and emotional profile and parental stress in preschool children with autism spectrum disorder. *Res Dev Disabil*. 2015;45-46:411-421.
<https://doi.org/10.1016/j.ridd.2015.08.006>
19. Lecavalier L, Leone S, Wiltz J. The impact of behavior problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*. 2006;50:172-183. <https://doi.org/10.1111/j.1365-2788.2005.00732.x>
20. Ingersoll B, Hambrick DZ. The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Res Autism Spectr Disord*. 2011;5(1):337-344.
<https://doi.org/10.1016/j.rasd.2010.04.017>
21. Rivard M, Terroux A, Parent-Boursier C, Mercier C. Determinants of stress in parents of children with autism spectrum disorders. *J Autism Dev Disord*. 2014;44(7):1609-1620.
<https://doi.org/10.1007/s10803-013-2028-z>
22. Yorke, I., White, P., Weston, A. *et al*. The association between emotional and behavioral problems in children with Autism Spectrum Disorder and psychological distress in their

- parents: A systematic review and meta-analysis. *J Autism Dev Disord* 48, 3393–3415 (2018).
<https://doi.org/10.1007/s10803-018-3605-y>
23. Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 43(6), 1380-1393
 24. Einfeld SL, Tonge BJ. Manual for the developmental behaviour checklist: primary carer version (DBC-P) & teacher version (DBC-T). University of New South Wales and Monash University; 2002.
 25. Snow AV, Lecavalier L. Sensitivity and specificity of the Modified Checklist for Autism in toddlers and the Social Communication Questionnaire in preschoolers suspected of having pervasive developmental disorders. *Autism*. 2008;12(6):627-644.
<https://doi.org/10.1177/1362361308097116>
 26. Sparrow SS, Cicchetti DV, Balla DA. *Vineland Adaptive Behavior Scales: Second edition (Vineland II), Survey Interview Form/Caregiver Rating Form*. Pearson Assessment; 2005.
 27. Bailey DB, Raspa M, Olmsted MG, et al. Development and psychometric validation of the Family Outcomes Survey-Revised. *J Early Interv*. 2011;33(1):6-23.
<https://doi.org/10.1177/1053815111399441>
 28. Abidin RR. Parenting stress index - Short form. Pediatric Psychology Press; 1990.
<https://doi.org/10.1037/t02445-000>
 29. Raspa M, Hebbeler K, Bailey D. *A Guide to Analyzing Data from the Family Outcomes Survey*. Early Childhood Outcomes Center; 2009.
 30. Cohen J. *Statistical Power Analysis for the Behavioral Sciences*. New York, NY: Routledge Academic; 1988.
 31. Taylor JL, DaWalt LS. Working toward a better understanding of the life experiences of women on the autism spectrum. *Autism*. 2020;24(5):1027-1030.
doi:10.1177/1362361320913754
 32. Hollocks MJ, Lerh JW, Magiati I, Meiser-Stedman R, Brugha TS. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychol Med*. 2019;49(4):559-572. doi:10.1017/S0033291718002283

33. Sedgewick F, Leppanen J, Tchanturia K. Gender differences in mental health prevalence in autism. *Advances in Autism*. 2020 Jun 6. <https://doi.org/10.1108/AIA-01-2020-0007>
34. Au-Yeung, SK, Bradley, L, Robertson, AE, Shaw, R, Baron-Cohen, S, & Cassidy, S. Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism*, 2019; 23(6), 1508-1518
<https://doi.org/10.1177/1362361318818167>

Table 1

Demographic Information for mothers and children (N = 40)

Demographic area	Mothers identifying as autistic (<i>n</i> = 20)		Mothers not identifying as autistic (<i>n</i> = 20)		Group comparisons	
	<i>n</i>	%	<i>n</i>	%		<i>p</i>
Maternal age range					<i>U</i> = 160	.21
21 – 30 years	0	0	1	5		
31 – 40 years	14	70	10	50		
41 – 50 years	6	30	9	45		
Maternal highest education level					<i>U</i> = 190	.28
Secondary school	5	25	6	30		
Tertiary education	15	75	14	70		
Maternal co-occurring diagnoses						
Speech or language disorder ^b	2	10	0	0	- ^c	.49
Learning disability ^b	1	5	0	0	- ^c	1.0
Mental health disorder	10	50	3	15	$\chi^2 = 6.92$.01
Intellectual disability ^b	0	0	0	0	-	-
Family income					<i>U</i> = 151.5	.22
AUD\$0 – \$37,000	2	10	1	5		
AUD\$37,001 – \$80,000	5	25	3	15		
AUD\$80,001 – \$180,000	12	60	12	60		
AUD\$180,001 and over	1	5	2	10		
Do not wish to answer	0	0	2	10		
Child gender					2.50 ^c	.114
Male	14	70	18	90		
Female	6	30	2	10		
Matching variables	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Child DBC-P Disruptive Behaviour ^a	22.90	12.53	22.95	12.64	0.013	.990
Child SCQ score ^b	21.45	6.25	21.40	5.43	-0.027	.979
Child VABS-II Receptive Communication ^c	9.40	3.98	10.15	3.44	0.638	.527

^aPercentages for maternal cooccurring conditions were based on total number in each group (*n* = 20).^bNot all participants provided an answer for this question.^cFishers exact used as expected cell count below 5